

Native American Monograph No. 1

# Documentation of the Cancer Research Needs of American Indians and Alaska Natives



NATIONAL INSTITUTES OF HEALTH  
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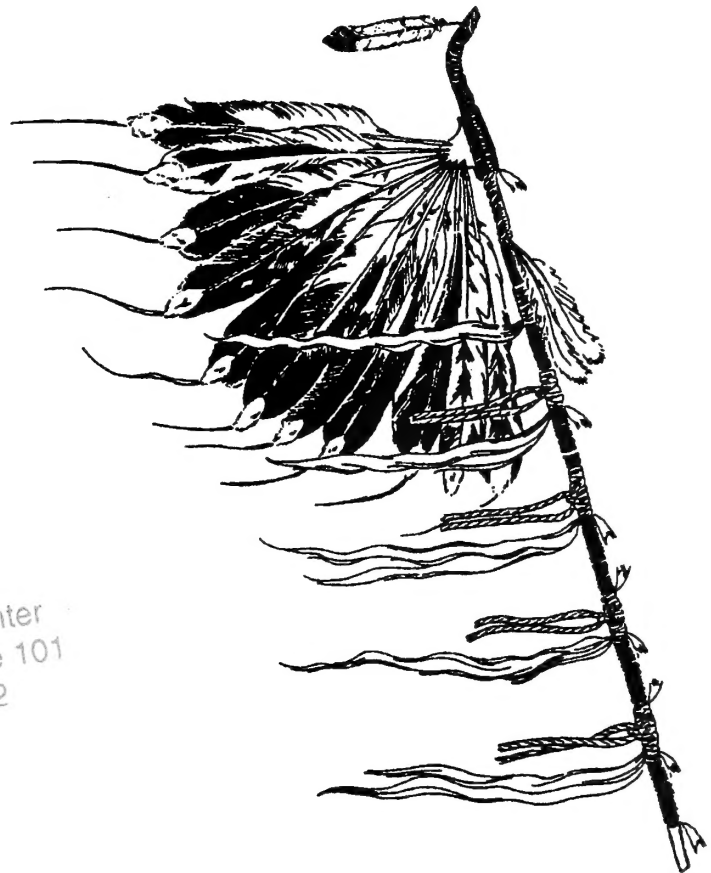
# **Documentation of the Cancer Research Needs of American Indians and Alaska Natives**

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## FOREWORD

The National Cancer Institute is committed to reducing cancer incidence and mortality among Indigenous Peoples. The commitment to reduce the suffering and death from cancer has been intensified where people suffer disproportionately from cancer or appear to be underserved. The Native American Cancer Control Initiatives are an important expression of this commitment.

The NCI Division of Cancer Prevention and Control has compiled an overview of NCI-supported Native American projects and they are detailed in this publication. Last year a workshop was held to encourage NCI Cancer Centers to link up with those concerned with the health of Native Americans and to train scientists to apply for grants in this area. A meeting was held in the summer of 1993 to discuss cancer control research among these populations. As long ago as 1987, NCI began to formally address the programs and activities needed to fulfill these goals. We hope that the overview of cancer among Indigenous Peoples provided in this book spurs targeted research.

We hope the reader will find this book has a useful emphasis on nutrition as it relates to cancer prevention and control. This is an important area. All lifestyle issues are interwoven with economics and in many cases also influenced by tradition. Nutrition and smoking certainly are influenced by both. NCI is encouraging innovative research that focuses on increased access to and consumption of fruits and vegetables and fiber to reduce the risk not only of cancer, but also the risk of cardiovascular disease, obesity and diabetes.

The NCI acknowledges the Sovereign Rights of the Indian Nations and wishes to work with these Nations in improving the quality of life, particularly in reducing cancer incidence and mortality, among Indigenous Peoples.

Finally, this monograph presents concepts that will assist in the establishment of culturally relevant and, hence, acceptable programs. There is extreme variability in these groups and we hope this book helps to sensitize program planners to this fact.

A handwritten signature in cursive script, reading "Samuel Broder".

Samuel Broder, M.D.

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In addition to comprehensive reviews, additional contributions have been included in this publication from Thomas Becker and Richard Clark. Their assistance made this publication possible.

## PREFACE

### Purpose

The **purpose** of this publication is to provide a resource and reference to assist in the formulation of culturally acceptable cancer prevention and control research projects or programs. It is a *brief* overview of the cancer problem among American Indian and Alaska Native People living in urban, rural, reservation and village sites. It is not designed to be read from cover to cover, but rather that the reader will utilize appropriate sections which may assist in the formulation of a cancer prevention and control program for one's local Native community. This document is neither all encompassing nor comprehensive, but rather is an introduction to the cancer problem as it currently exists among American Indians and Alaska Natives. Because specific tribal information is rarely available, reservations, urban Indian clinics and other tribal settings are encouraged to collect and record cancer data for their community.

This publication is the first of a series of monographs which focus on Native Americans. Monograph #1, *Documentation of the Cancer Research Needs of American Indians and Alaska Natives* provides an overview of cancer among Indigenous Peoples. The monograph has three sections: the initial section is a brief overview of cancer among Indigenous Peoples; the second section describes the role of nutrition in cancer prevention and control; and, the third section is an overview of NCI-supported Native American projects and activities. It is designed to be used as a resource or reference to assist in the formulation of culturally competent cancer prevention and control research projects or programs.

### Target Audience for this Publication

This monograph is primarily designed for use by Native and non-Native cancer researchers. Basic information on cancer data and cancer research is included to assist the researcher who is new to the field. Information in this publication may also be of assistance to health care providers, tribal health planners, health educators, public health nutritionists, community health representatives, and other similar professionals working with American Indian or Alaska Native populations in developing and designing cancer prevention and control research proposals, programs, and/or materials.

The information from this publication may benefit Native researchers in the development and implementation of cancer intervention programs in urban, rural and/or reservation settings. It may assist in the development of culturally competent Native American survey instruments for the collection of accurate data. It may also be useful in the development of culturally sensitive Native American cancer education materials and programs to be used in innovative research interventions.

### The Native American Populations

When the National Cancer Institute (NCI) specifies, "Native American", the following populations are included: American Indians, Alaska Natives, Native Hawaiians and American

Samoans. This publication focuses on two of these populations: American Indians and Alaska Natives only. Subsequent publications will focus on Native Hawaiians and American Samoans.

### **Limitations of this Publication**

This monograph is the first of a series of proposed publications which are designed to be of assistance to program planners, researchers and Tribal Councils and Boards. It is not possible to include everything one needs to know about the research process in one monograph. For your information, the suggested monographs include the following:

- Monograph #1: Documentation of the Cancer Research Needs of American Indians and Alaska Natives
- Monograph #2: Documentation of the Cancer Research Needs of Native Hawaiians and American Samoans
- Monograph #3: Cancer Risk Factors among Native Americans
- Monograph #4: Planning Cancer Prevention Research Projects among Native American Populations
- Monograph #5: Initiating Local Native Support for Cancer Prevention and Control Programs
- Monograph #6: Participation with and recruitment of Native Americans in Clinical Trials and other types of Research Projects

Since a future monograph is planned to focus on cancer risk factors among Native Americans, this monograph is limited in its discussion of those factors. The only risk factors which are included in any detail are dietary (Section II, Chapters 6, 7, and 8).

The Special Populations Studies Branch of NCI has planned to produce a *Bibliography of Native American Cancer and Cancer-related Literature* in the near future. This would include listings of references which will be of assistance to the researcher and others. The proposed Bibliography will not focus on Native American diet. For that reason, Section II of this monograph includes an extensive list of references on dietary components and cancer. Appendices "G" and "H" include additional resources.

### **Recommended Resources**

For general cancer information, the reader is referred to the Cancer Information Services which are located throughout the country. The toll free telephone number is 1 (800) 4-CANCER or 1 (800) 422-6237. Another excellent resource is *Cancer Statistics Review: 1973-1989* (NIH Publication number 92-2789) for a clear description of how NCI calculates rates and for comprehensive tables of cancer data.

Native American-specific cancer information is available through Dr. Sarah Valway's work, *Cancer Mortality among Native Americans in the United States; Regional Differences in Indian Health, 1984-1988; Trends Over Time, 1968-87*). This publication was released in 1992 and is available from the Cancer Prevention and Control Program located in Indian Health Service Headquarters West, Albuquerque, New Mexico. Their phone number is 1 (505) 766-5557.

The proceedings from the 1989 First National Conference on Cancer in Native Americans are published in the *American Indian Culture and Research Journal* (volume 16, number 3, 1992) which is published at UCLA.

For listings of Native American cancer publications, Dr. James Justice, who is with the Native American Research and Training Center, University of Arizona, has multiple works available which list American Indian bibliographies and literature.

### **Data Issues**

At the present time, there is a dearth of accurate data on cancer among American Indians and Alaska Natives which is accessible to Indigenous Peoples. The National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) database is a basic resource for information about cancer incidence and mortality rates. The geographic areas comprising the SEER Program's database, represent an estimated 9.6% of the United States population.<sup>1</sup> American Indian residents from Arizona were added in 1980. The New Mexico SEER Registry includes American Indians and Alaska Natives from both New Mexico and Arizona which contain about 19 percent of the American Indian population, but these data are not representative of American Indians elsewhere. This poses difficulties due to a high rate of variation in Native American culture and lifestyle patterns, i.e., smoking prevalence, access to medical care, and the poverty level. For example, American Indians who live in Arizona and New Mexico rarely use tobacco, and therefore lung cancer rates from the New Mexico SEER Registry cannot be uniformly generalized to represent other Native Americans. For the present, SEER rates must be read for Native American populations with this caution in mind. While developing a cancer program for Indigenous Peoples from geographic areas outside of SEER regions, such as the North Central States (sometimes referred to as the Northern Plains), researchers must rely on statistics from federal agencies such as the Indian Health Service and National Center for Health Statistics.



## TERMINOLOGY

**Age-adjusted rate:** Cancer risk increases with age. The purpose in calculating an "age-adjusted rate" is to remove the effect of age differential to allow for comparisons of rates among different population groups. For example, cancer mortality rates in Florida and North Dakota need to be adjusted for age if they are to be compared. Florida has a higher proportion of older people than does North Dakota. Thus, a higher unadjusted rate of cancer would be observed in that state versus in North Dakota. Age adjustment takes into account the different population structures and allows comparisons of rates. (see "rate" below; for additional descriptions of age adjustment, see reference #2<sup>2</sup>)

**Alaska Native:** The term collectively refers to Eskimos, Aleuts and American Indians who are indigenous to Alaska.

**All Races:** This is a phrase which is used to describe the entire U.S. Population (including American Indians, Aleuts, Eskimos, whites, black Americans, Asians, Hispanics, Latinos, Native Hawaiians, et al).

**American Indian:** This includes enrolled members of Federal and/or state recognized tribes as well as people who are self-identified as "American Indian" on the U.S. Census. The degree of Indian blood in these self-identified Indians is not known. Many tribes have a tribal-specific blood quantum requirement (e.g., one-quarter) for membership; some tribes have a simple descentance requirement.<sup>3</sup>

**Benign:** not recurrent; not malignant; mild;<sup>4</sup> (an adjective) in pathology terms, refers to non-malignant, usually in reference to tumors.

**Blood Quantum:** Indicates the percentage of American Indian or Alaska Native. For example, a mother who is 50 percent or one-half blood quantum is half American Indian and half some other race. If this mother and a white father parent a child, the child has a blood quantum of 25 percent or one-quarter. Some persons may be of mixed American Indian tribal descentance and must indicate their principal tribe on Census and other questionnaires.

---

## ABBREVIATIONS

<b>CDC</b>	Centers for Disease Control and Prevention
<b>IHS</b>	Indian Health Service
<b>NCHS</b>	National Center for Health Statistics
<b>NCI</b>	National Cancer Institute
<b>NHANES</b>	National Health and Nutrition Examination Survey
<b>NIH</b>	National Institutes of Health
<b>Pap</b>	Papanicolaou (smear or test)
<b>SEER</b>	Surveillance, Epidemiology, and End Results (Program)
<b>SES</b>	Socioeconomic status

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**Carcinogen:** Any cancer-causing substance or agent.

**Carcinoma:** A cancer that arises in the epithelial cells. These cells are in skin and other tissues that cover external and internal body surfaces.

**Federally Recognized Tribes:** Refers to the relationship between certain Indian tribes and the Federal Government. Federal recognition can be obtained by satisfying the criteria of the Federal Acknowledgement Process administered through the U.S. Department of the Interior, by Federal statute enacted by Congress, or by federal court decree. Federally recognized tribes and their members are eligible for the special programs provided by the United States for Indian people because of their status as Sovereign Nations of Indians.<sup>3</sup>

**Federal Definition of "American Indian":** "Any person who is a member of an Indian tribe, as defined in subsection (d) hereof, except that, for the purpose of sections 102, 103, and 20 (c) (5), such terms shall mean any individual who (1) irrespective of whether he or she lives on or near a reservation, is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now or in the future by the state in which they reside, or who is a descendant, in the first or second degree, of any such members, or (2) is an Eskimo or Aleut or other Alaska Native, or (3) is considered by the Secretary of the Interior to be an Indian for any purpose, or (4) is determined to be an Indian under regulations promulgated by the Secretary."<sup>5</sup>

**Incidence:** Refers to a rate, based on identification of new cases of a specific disease occurring during a certain period in a defined population; usually expressed as new cases per 100,000 population per year, (see "rate" below).

**Indian Country:** (a) all land within the limits of any Indian reservation under the jurisdiction of the U.S. government; (b) all dependent Indian communities within the borders of the U.S.; (c) all Indian allotments (U.S. Congress, Indian Country Statute of 1948 (18 USC, 1151))

**Indian Territory:** This refers to Oklahoma lands which the U.S. Government historically set aside for American Indian tribes.

**Indian Tribe:** Any Indian tribe, band, nation, rancheria, pueblo or other organized group or community, including any Alaska Native village or group or regional or village corporation as defined in or established pursuant to the Alaska Native Claims Settlement Act (85 Stat. 688), which is recognized as eligible for the special programs and services provided by the United States to Indians because of their status as Indians. A tribe may be federally-recognized, state-recognized, or self-recognized and/or federally terminated.

**Indigenous Peoples:** The inhabitants of the North American continent prior to 1492; Living or occurring naturally in a specific area or environment<sup>6</sup>; The First Americans.

**Malignant:** Virulent; growing worse; resisting treatment, said of cancerous growths; tending or threatening to produce death; harmful.<sup>4</sup> An adjective; in pathologic terms, refers to cancer, a cellular growth which is tending or threatening invasion, destruction and tendency to spread; opposed to benign tumors.

**Metastasis:** Movement of bacteria or body cells (especially cancer cells) from one part of the body to another; change in location of a disease or of its manifestations or transfer from one organ or part to another not directly connected. The usual application is to the manifestation of a malignancy in a secondary growth arising from the primary growth in a new location. Spread is by the lymphatic or blood stream.<sup>4</sup> Spread of cancer cell from a primary tumor to sites elsewhere in the body.

**Morbidity:** State of being diseased. The number of sick persons or cases of disease in relationship to a specific population.<sup>4</sup> Illness; can also refer to morbidity rate, which is the number of illnesses occurring during a certain period of time, usually a year, per unit of population, usually 1,000 or 10,000 or 100,000; usually expressed as the number of new illnesses per 100,000 population per year. (See "rate" below)

**Mortality:** Death; refers to a rate based on the number of deaths occurring during a certain period in a defined population; rates are calculated as number of deaths per 100,000 population per year. (See "rate" below)

**Native American:** The term collectively includes American Indians, Alaska Natives, and Native Hawaiians. However, in this publication, the term only refers to American Indians and Alaska Natives.

**Non-Natives:** Refers to people who are not recognized as or do not identify themselves as American Indian or Alaska Native.

**Person-years:** Person-years may be used as the denominator for the computation of incidence or mortality rates. Person-years of observation are frequently used as denominators in the computation of rates in prospective studies. They take into consideration both the number of persons who were observed and the duration of observation of each person. For example, five persons who remain under observation for twenty years contribute one hundred person-years of observation and one hundred persons who are observed for one year also contribute one hundred person-years of observation.<sup>7</sup>

**Population-based:** Disease incidence and mortality data based on the number of persons in a given geographic location.

**Rate:** Rates form the essential ingredients of vital statistics methods. For mortality, the numerator of a death rate for some period of time is a count of deaths during that time period as reported to local and, subsequently, to national authorities. The denominator is the population at risk during that time period as determined by census, special population enumerations, and the reporting and recording of births.<sup>8</sup> Rates differ from ratios, proportions and percentages in that which their numerators are accumulated over a period of time (usually a year), their denominators are static figures estimating the population at one point in time.<sup>2</sup> Refers to the force of a disease in a population; is similar to risk of developing a disease. Rates are calculated by including the number of new cases of disease which occur in a population (the numerator) in a given period of time, and dividing that number by a denominator which includes both persons at risk to develop the disease and time at risk. If 50 new cases of cancer occurred in a population of 5,000 people during a one-year period, the crude (unadjusted) incidence rate would be  $50 \div 5000$  person-years, or 0.01 cases per person-years.

years. Through simple multiplication, this rate can be defined in terms of a standard denominator, such as 100,000 per person-years. Thus, 0.01 cases per person-year = 1000 cases per 100,000 person years. A high rate implies a strong force of a disease in a population. This term is commonly used in reference to both morbidity and mortality (see above). For additional information on rates and rate calculations, see reference #2 and #8).

**Relative survival rate:** The relative survival rate is calculated using a procedure described Ederer, Axtell and Cutler (1961). This involved adjusting the observed survival rate for expected mortality. The relative survival rate represents the likelihood that a patient will not die from causes associated specifically with their cancer at some specified time after diagnosis.<sup>1</sup>

**Reservation:** The geographic area set aside by treaty or other law for a federally recognized Indian tribe, including Pueblos, rancherias, or colonies, informal reservations in Oklahoma, Alaska Native regions established pursuant to the Alaska Native Claims Settlement Act (43 U.S.C. 1601 et seq.).<sup>3</sup>

**Reservation State:** A state in which there is at least one federally recognized Indian reservation or tribe(s) and in which IHS provides services or fiscal support for health care for eligible Indians.<sup>3</sup> As of 1992, there are 33 such states.

**Sarcoma:** A cancer of mesenchymal origin found in tissue (e.g., muscles, bone, cartilage).

**Self-determination:** A policy established in 1975 with the Indian Self-Determination and Education Assistance Act (Public Law 93-638) to encourage maximum Indian participation in the planning, conduct, and administration of Federal programs and services provided for Indians by Indian Health Service (IHS) and Bureau of Indian Affairs (BIA), by transferring responsibilities for these programs and services from the Federal Government to tribal governments which were established under the Indian Reorganization Act (25, USC 461-479).<sup>3</sup>

**Terminated Tribes:** Refers to Federal policy after World War II and continuing into the 1960's, formally repudiated by Congress in 1989, which had several components: (1) induced resettlement of thousands of reservation Indians to urban centers where they were to be trained and employed; (2) the transfer of major functions, responsibilities, and jurisdiction over Indians to states from the Federal Government; and (3) the termination of the Federal relationship with specific tribes, including ending services and distributing tribal assets to tribal members.<sup>3</sup>

**Tribal Enrollment Number:** Each tribe determines the criteria by which individuals are accepted as a member of the tribe. In many tribes it is a minimal blood quantum, such as 25 percent, or one-quarter. In a few, it is proof of Indian ancestry. In others it is proof of ancestors being included on the Department of the Interior's Records from the late 1800's and early 1900's which was to register all "legal" Indians. An example of an illegal Indian is one who committed a crime and was not allowed to be listed or counted in the Department of Interior's book. Each tribe, as a Sovereign Nation, determines its own criteria for acceptance of tribal members to be included on tribal enrollment books. All entries on these books receive enrollment numbers.

**Tribal Trust Land:** Lands held in trust for Indian tribes and administered for their mutual benefit by the Federal Government.<sup>3</sup>

**93-638 Clinics:** Health clinics owned and operated by Native Americans, tribes or Alaska Native Health Corporations; a health clinic which is owned, staffed, and managed by local tribal communities. The 1975 Indian Self-Determination Act, P.L. 93-638 and the 1976 Indian Health Care Improvement Act, P.L. 94-437 as amended, allow for higher resource levels to expand health services, to build and renovate medical facilities, and for the construction of safe drinking water and sanitary disposal facilities. These "638" clinics may receive part of their funding from the IHS. **Note:** some American Indian and Alaska Native owned and operated clinics are *not* 93-638 clinics.

**93-638 Contracts:** Indian and owned and operated clinics who are contracted via the 93-638 process; contracts between Indian tribes or tribal organizations and Federal agencies (i.e., IHS and BIA), under which tribes assume planning, operation, and administration of programs and services for Indians from the Federal Government.<sup>3</sup>

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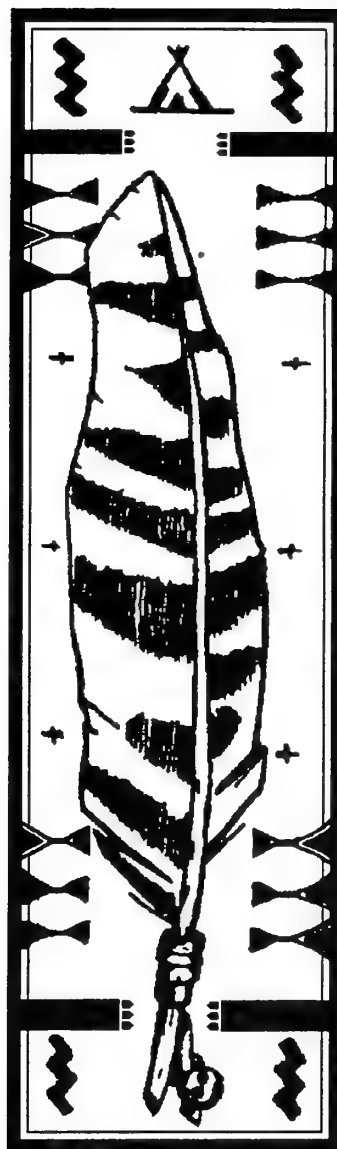
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# SECTION I

## OVERVIEW OF CANCER AMONG INDIGENOUS PEOPLES

The first section of this publication provides an overview of American Indian and Alaska Native populations, a description of cancer databases and their limitations, an explanation of cancer incidence, mortality and survival data for American Indians and Alaska Natives, clarification regarding the regional variation of cancer among Indigenous Peoples from different geographic regions and tribal affiliations. The last chapter of this section provides a summary chart of risk factors for the eight cancer sites which are common among Native Americans and a brief discussion of tobacco use among Native Americans.







# CHAPTER 1: INTRODUCTION AND BACKGROUND

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## CHAPTER OBJECTIVES:

- DESCRIBE NATIVE AMERICAN CULTURAL PRACTICES WHICH MAY AFFECT CANCER PREVENTION AND CONTROL RESEARCH PROJECTS
  - DELINEATE AMERICAN INDIAN AND ALASKA NATIVE DEMOGRAPHICS
  - DESCRIBE NATIVE AMERICAN ISSUES RELATED TO ACCESS TO MEDICAL SERVICES
- 

## INTRODUCTION

This first chapter includes a brief overview of current conditions among American Indians and Alaska Natives, as well as a summary of cultural features, beliefs, demographics, and access to health care services. The criteria for inclusion of information in this introductory section are relevancy to cancer prevention and control programs among American Indians and Alaska Natives.

### **Brief overview of cancer among American Indians and Alaska Natives**

According to the New Mexico SEER Registry, American Indians living in New Mexico and Arizona have incidence rates for stomach, cervix uteri, primary liver, and gallbladder cancers that are higher than for U.S. population. American Indians experience excessive mortality rates from cervical and gallbladder cancers when compared with SEER white rates. The cancer survival rates for American Indians are among the poorest of any racial group in the United States. The five-year relative survival data collected among American Indians are poorer for all cancer sites combined. Compared to non-Indian peoples in the Southwest, even when cancer is diagnosed in early stages (i.e., Stage II), when stage at diagnosis and treatment is considered, survival from cancer for American Indians is poor.<sup>1</sup> Survival data are from American Indians living in New Mexico and Arizona only, and data are not yet available for American Indians or Alaska Natives in other parts of the country.

Data from the Alaska Native Tumor Registry suggest that Alaska Natives have excessive cancer incidence of cervix uteri, colon and rectum, gallbladder, kidney, nasopharynx, oral cavity and pharynx. The annual age-adjusted cancer death rates

(156/100,000) for the Alaska Indian Health Service (IHS) Area exceed those of the U.S. All Races (132/100,000)<sup>2</sup>. Alaska Natives have excessive mortality from cancers of the cervix uteri, colon and rectum, esophagus, gallbladder, kidney, nasopharynx, and salivary glands. Colorectal, breast, pancreas and cervical cancers are the most frequent causes of cancer death among Alaska women. Stomach cancer incidence and mortality are excessive for Alaska Native males when compared with white males. Alaska Natives have the highest mortality rates of any racial group for cancers of the oral cavity, colon and rectum, gallbladder, corpus uteri, and renal system. Survival data for Alaska Natives living in Alaska are in the process of being collected, but presently are unavailable.

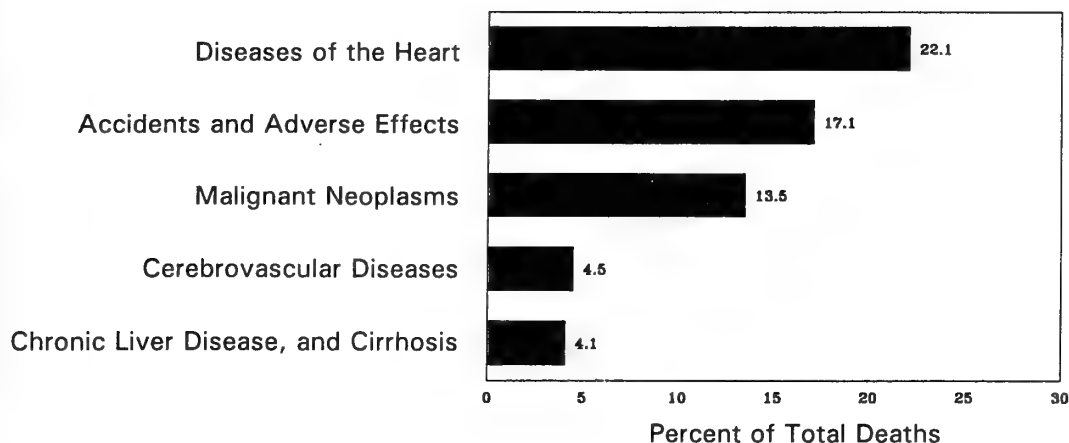
The poor survival rate of American Indians reported by the National Cancer Institute (NCI) suggests that American Indian cancer patients experience the disease differently from those in Non-Native populations. To further explore these issues, factors such as genetic risk factors, late detection of cancer, poor compliance with recommended treatment, presence of concomitant disease, or lack of timely access to state-of-the-art diagnostic and/or treatment methods should be investigated.

By studying cancer within American Indian and Alaska Native populations, scientists have the opportunity to learn about the disease itself which may be of assistance to people of all races. For example, cervical cancer incidence rates are high among American Indian women when compared with white women from the same geographic regions. However, American Indian women do not appear to have many of the risk factors which are commonly associated with cervical neoplasia among non-Native populations<sup>3</sup>. It is not known if genetics play a more significant role in cervical cancer within American Indian women as compared to non-Native women. Research is needed to improve understanding of the risk factors and the determinants of cervical cancer incidence among American Indians and Alaska Natives. Such data would benefit women of all races.

## **BACKGROUND ON AMERICAN INDIANS AND ALASKA NATIVES**

At the turn of this century, cancer was a rare disease among American Indian people.<sup>4</sup> According to a number of articles reviewed at the beginning of this century (Levin 1910), American Indians *never* had cancer.<sup>4</sup> This was an erroneous conclusion, however, since cancer has been identified in skeletal remains found in archaeological investigations of Indian burial grounds.

The leading causes of death among American Indians and Alaska Natives in 1986-1988 for all IHS Areas are illustrated on Graph 1.1 on the following page.<sup>5</sup> Although American Indians and Alaska Natives continue to experience low cancer incidence rates in comparison with other racial groups such as whites, blacks, and Asians, within the last few generations, cancer has become the leading cause of death for Alaska Native women, and is the second leading cause of death among American Indian women.<sup>6, 7</sup> Within the last thirty years, cancer has become the third leading cause of death for American Indians and Alaska Natives of all ages,<sup>8</sup> and it is the second leading cause of death among American Indians over age 45 years.<sup>6</sup>

Graph 1.1: Leading Causes of Death: All IHS Areas for Calendar Year 1986-1988<sup>5</sup>

#### **National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives**

Individuals who are interested in cancer research priorities among Indigenous Peoples may find the "*National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives*" to be of assistance. This plan was prepared by the National Cancer Institute-supported *Network for Cancer Control Research among American Indian and Alaska Native Populations*. The purpose of this plan was to enhance the awareness in federal agencies and in others (e.g., State Departments of Public Health) about the problems of cancer among American Indian and Alaska Native populations. The Plan includes:

- An executive summary
- Introduction
- Overview of the Plan's issues and recommendations for federal agencies
- Action items
- Outcome measures

Cancer among Indigenous Peoples is emphasized in the Plan in its discussions of the poor cervical and breast cancer survival rates, the lack of access to early detection services, the lack of Indigenous health care providers and researchers, and the cultural barriers which interfere with effective cancer prevention and control programs. This Plan is included in its entirety in Chapter 12 of this publication.

## **Health Priorities among American Indians and Alaska Natives**

Although cancer is an increasing health problem among Indigenous Peoples, a wide variety of health issues compete for attention within most Native American communities. It is challenging to raise "cancer" on the health agenda of Native communities where health priorities include alcohol/substance abuse, violence, accidents, suicide, diabetes, obesity, and cardiovascular disease. In addition, "cancer" as a problem is competing against poverty, shelter, unemployment, clothing needs, and access to sufficient nutritional foods such as fruits and vegetables for one's family and neighbors.

Despite the many cultural strengths associated with tribal membership, the current health status of American Indian and Alaska Native Peoples is significantly inferior to that of non-Indian populations. For example, general mortality rates from tuberculosis are 780 percent greater among American Indians than the U.S. rate; alcoholism are 663 percent greater for American Indians than for the U.S. population, accidents are 295 percent greater among Indigenous Peoples, diabetes is 268 percent greater than among U.S. population, homicide rates are 134 percent greater among American Indians, and suicide rates are 95 percent greater among Native Peoples than among U.S. populations.<sup>5</sup>

## **DEMOGRAPHICS**

The Bureau of the Census has prepared a detailed analysis of 1990 American Indian Alaska Native data which is tentatively scheduled to be available during the latter part of 1993. The 1990 Census data were utilized in the following section when feasible. Some descriptive information is based on 1980 Census if specific 1990 data have not yet been released by the Census Bureau.

### **Age**

In 1986-1988, the life expectancy at birth for nine of the IHS service areas (including Alaska) was 70.1 years, which was 4.9 years less than the 1987 estimate of 75.0 for U.S. All Races population.<sup>5</sup> Only 5.6 percent of people who were self-identified as American Indians and Alaska Natives on the 1990 Census were older than 65 years of age. Approximately 14 percent of whites were over 65 years of age. At the time of the 1990 Census, a lower percent of American Indian and Alaska Native women (6.5 percent) were 65 years or older compared with American Indian and Alaska Native males (4.8 percent).<sup>9</sup>

According to the 1980 Census, the median age of American Indians a decade ago was 23.4 years, which is almost seven years younger than the average U.S. population figure of 30 years. Indians living on reservations were even younger, with a median age of 19.7 years. The median age of Alaska Natives was 21 years, compared with 26 years for the total Alaska state population and with 30 years for the average U.S. population. The life expectancy of Alaska Natives was 67 years.<sup>10</sup>

### **Poverty**

In 1989, twice as many American Indians and Alaska Natives (30.9 percent) as the total U.S. population (13.1 percent) lived at or below the poverty level. The percent of whites living at or below poverty level in 1989 was 9.8 percent. The median family income in 1989

for Indigenous Peoples was \$20,025. The white median family income was \$31,435 in 1989.<sup>11</sup> Similar to other Native American groups, the socioeconomic conditions of Alaska Natives are poor. In 1980, approximately one-fourth of Alaska Native families lived below the poverty level.

### **Employment**

According to the 1990 Census, 62.1 percent of Indigenous Peoples 16 years and older are in the labor force, of which 10.3 percent are in the armed forces and 14.4 percent are unemployed. The unemployment percent for whites was 5.2.<sup>11</sup> The unemployment rates among Indians living on reservations was higher than for Indians living in urban areas. A large proportion of American Indians have left reservations to get jobs that pay enough to support families.

### **Education**

According to 1990 Census data, 65.5 percent of all American Indians and Alaska Natives age 25 and over completed at least four years of high school and 9.3 percent possess a bachelor's degree or higher. In comparison, 77.9 percent of whites complete high school or higher and 21.5 percent have a bachelor's degree or higher.<sup>11</sup> Approximately 85 percent of Indian youth attend public schools, 10 percent attend Bureau of Indian Affairs (BIA) schools, and 5 percent attend private schools.

Based upon 1980 Census, 18 percent of Alaska Natives ages 25 year or older had less than five years of elementary school, as compared with 2.6 percent of U.S. whites. Of the Alaska Natives 25 years or older, 46 percent had completed high school, in comparison to eighty-three percent statewide. Less than 4 percent of Alaska Natives were college graduates, in comparison with 21 percent statewide.<sup>10</sup>

### **Geographic Distribution - American Indians**

There were approximately one million Native People on the continent at the time of Columbus; at the turn of this century there were only 200,000.<sup>12</sup> Today, the "American Indian" (which includes all tribes and clans of peoples who are Indigenous to continental U.S.) has the smallest number of people among identified racial groups in the United States. Approximately 1.9 million people (0.8 percent of the U.S. population) were self identified as American Indians and Alaska Natives on the 1990 U.S. Census.<sup>13</sup> Although over 700 tribes of Indigenous Peoples originally inhabited this land, at least 200 tribes have become extinct. In 1988 the Bureau of Indian Affairs Federal Register listed and recognized approximately 500 tribes of Native People in the U.S.

Each of the surviving federally recognized tribes has its own unique and diverse culture and many are acknowledged by U.S. Congress as Sovereign Nations. In addition, there are hundreds of tribes which are recognized by individual states, but not by the federal government. An Act of Congress is required to formally "recognize" a tribe today. Many tribes no longer possess reservation or trust lands and several tribes share a single reservation. A map which illustrates the location of federal reservations is included in Figure 1.1 and the locations of the twelve Alaska Native Health Corporations is included in Figure 1.2.

Figure 1.1 The location of federally - recognized reservations and tribes.

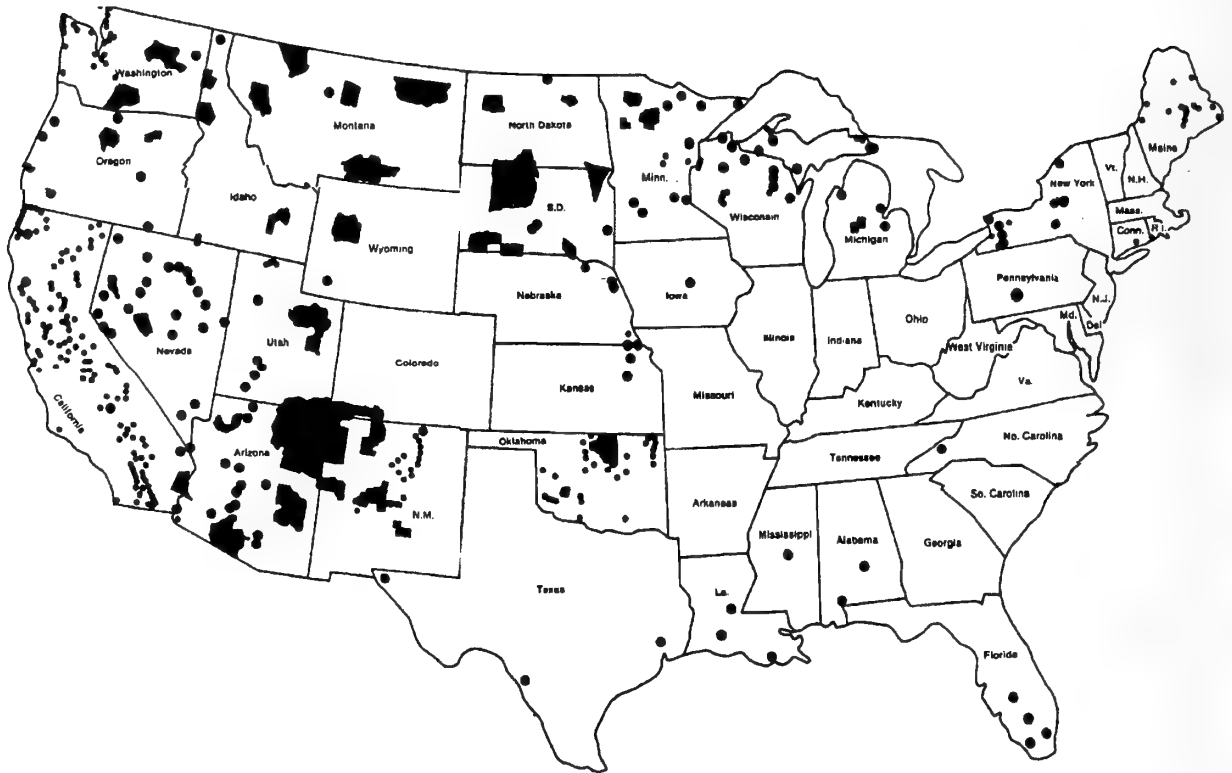
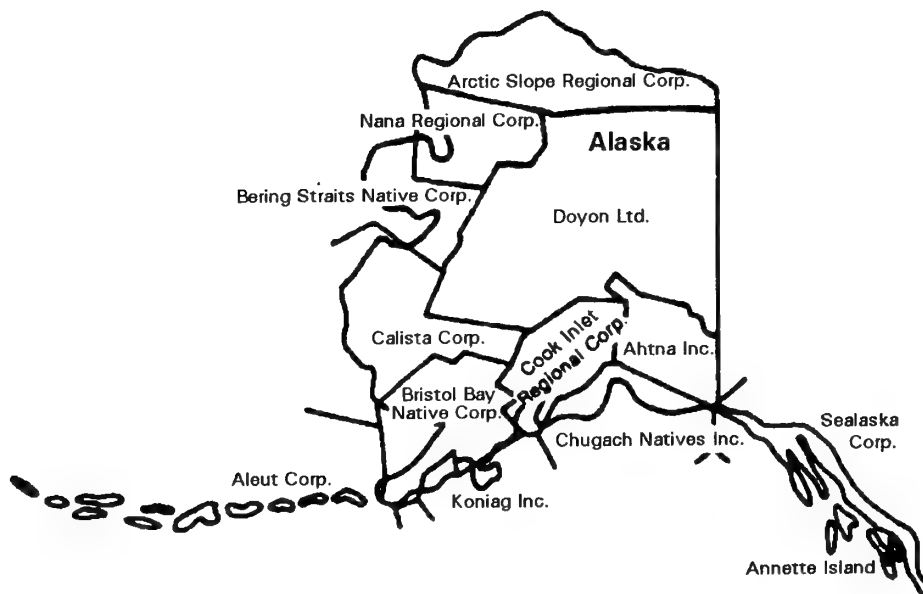


Figure 1.2 The location of Alaska Native Health Corporations.



There are 314 federal reservations and trust lands, 217 Alaska Native village statistical areas, 12 Alaska Native regional corporations, and 17 tribal jurisdiction statistical areas (which used to be referred to as the "historic areas of Oklahoma, excluding urbanized areas").<sup>14</sup>

About one-half of the American Indian population lived in the West in 1980, 27 percent in the South, 18 percent in the Midwest, and 6 percent in the Northeast (1990 Census data unavailable).<sup>10</sup>

American Indian people reside in every state. According to the 1990 Census, the states which have over 50,000 self-identified American Indians include the following: Oklahoma (252,420), California (242,164), Arizona (203,527), New Mexico (134,355), Alaska (85,698), Washington (81,483), North Carolina (80,155), Texas (65,877), New York (62,651), Michigan (55,638), and South Dakota (50,575).<sup>15</sup>

According to 1990 Census, the ten largest American Indian tribes are Cherokee (308,132), Navajo (219,198), Chippewa (103,826), Sioux (103,255), Choctaw (82,299), Pueblo (52,939), Apache (50,051), Iroquois (49,038), Lumbee (48,444), and Creek (43,550). Tribal members report residence in states in addition to the location of their home reservation. For example, 42.5 percent of the Sioux live in South Dakota, which is the location of Pine Ridge and Rosebud reservations. In addition, 7.3 percent of the self-identified Sioux on the 1990 Census live in California, 6.8 percent live in North Dakota, and 5.3 percent live in Minnesota.<sup>16</sup>

### *American Indians on Reservations*

A reservation is an area of land held in trust by the federal government reserved for Indian use. However, according to the 1990 Census, of the 637,533 people living on Indian reservations, 60.9 percent are Indians and 39.1 percent are non-Indians. The Secretary of the Interior is the trustee for the U.S. federal government and the Bureau of Indian Affairs is responsible for the administration and management of Indian trust lands to the trustee.<sup>17</sup>

Contrary to popular opinion, according to the 1990 Census, only 19.8 percent of all American Indians live on a Federal reservations. According to the 1990 Census, the ten largest reservations and their respective populations are listed in Table 1.1.<sup>17</sup>

To illustrate the poverty level experienced by people living on those reservations a few data are presented:<sup>10</sup>

- Almost one-fourth of American Indian housing units lacked complete plumbing facilities.
- At least 50 percent of the homes on three of the largest reservations--Hopi, Tohono O'Odham, and Navajo--were without an indoor toilet.
- More than half (56 percent) of the American Indian housing units on ten of the largest reservations had no telephone.
- Sixteen percent of all American Indian housing units on reservations lacked electric lighting.
- Nearly 50 percent of the American Indian housing units on the Hopi and Navajo were without electric lighting.

**Table 1.1 Ten Largest American Indian Reservations**

<b>10 Largest Reservations</b>	<b>Total Population</b>	<b>Native American Population</b>
Navajo and Trust Land AZ, NM UT	148,451	143,405 (96.6%)
Pine Ridge and Trust Lands NE SD	12,215	11,182 (91.5%)
Fort Apache AZ	10,394	9,825 (94.5%)
Gila River AZ	9,540	9,116 (95.6%)
Tohono O'Odham AZ	8,730	8,480 (97.1%)
Rose Bud and Trust Land SD	9,696	8,043 (83.0%)
San Carlos AZ	7,294	7,110 (97.5%)
Zuni Pueblo AZ NM	7,412	7,073 (95.4%)
Hopi and Trust Lands AZ	7,360	7,061 (95.9%)
Blackfeet MT	8,549	7,025 (82.2%)

*American Indians in Urban and Rural Areas*

It is estimated that approximately 20 percent of American Indians live on tribal trust lands, 8 percent live on Historic Areas of Oklahoma, and another 3 percent live in Alaska Native Villages or rural areas.

Over 70 percent of the American Indian population lives off reservation or tribal trust lands, and over half live in urban areas. In the early 1950's, the Bureau of Indian Affairs monitored the "Relocation Program for American Indians" with the stated purpose of improving the status of living. Today, some urban Indian survivors of the 1950 Relocation Program are "second generation" to the city life and may or may not possess traditional cultural behaviors. Others are first generation urban residents. Some Indian people "migrate" back and forth from urban areas and to home reservations.

Indian people come to the cities for different reasons. Perhaps the most common reason is to secure employment. Others are forced to temporarily move to the city to obtain medical treatment that is not available on their home reservation. Or, as part of a rehabilitation program, a reservation American Indian may live in an urban area for six months to a year to maintain sobriety before returning to the home reservations.

**Geographic Distribution - Alaska**

Approximately one-third of Alaska Natives live in urban areas, primarily Anchorage, Fairbanks, and Juneau. The other two-thirds of the Alaska Native population live in one of more than 200 rural villages with populations of 50 to 1,000 people. Alaska Natives also live in the "lower 48" states, especially the northwestern states and California.



## Tribes and Bands - Alaska

The 1990 Census enumerated 85,698 American Indians, Eskimos and Aleuts living in Alaska. Approximately one-seventh of Alaska's population is Native. Over one-half of these are Eskimo, approximately one-third are American Indian and slightly more than one-tenth are Aleut. The two main Eskimo groups are Inupiat and Yupik. The primary language among many of these groups is the Native tongue rather than English. The primary American Indian tribes living in Alaska are Athapaskan, Tlingit, Tsimshian, and Haida.<sup>10</sup>

According the 1990 Census, the ten largest Alaska Native Village Statistical Areas follow:<sup>17</sup>

**Table 1.2 Ten Largest Alaska Native Village Statistical Areas**

<b>10 Largest Alaska Native Village Statistical Areas</b>	<b>Total Population</b>	<b>Alaska Native Population</b>
Bethel	4,674	2,986 (63.9%)
Kotzebue	2,751	2,067 (75.1%)
Barrow	2,763	1,771 (64.1%)
Dillingham	2,017	1,125 (55.8%)
Hooper Bay	845	811 (96.0%)
Mountain Village	674	614 (91.9%)
Emmonak	642	591 (92.1%)
Point Hope	639	587 (91.9%)
Unalakleet	714	584 (81.8%)
Selawik	596	569 (95.5%)

## ACCESS TO HEALTH SERVICES

Little data exist which describe access to health care. Although American Indians and Alaska Natives are eligible to receive comprehensive health services free of charge from the Indian Health Service (IHS), over half of Indigenous Peoples do not utilize IHS services. For those who do not take advantage of IHS facilities, the more common reasons are that they have medical insurance or that no IHS facility is accessible. For example, American Indians or Alaska Natives living in California (which is a reservation state and the state with the second largest number of Indigenous Peoples) cannot utilize IHS facilities because none exist within the state. A brief description of health care services is provided.

### The Indian Health Service (IHS)

The Indian Health Service (IHS) was established under the Transfer Act of 1954 (Public Law 83-568). This act mandated that the "conservation of Indian health all functions,

responsibilities, authorities, and duties relating to the maintenance and operation of hospital and health facilities for Indians be administered by the Surgeon General of the U.S. Public Health Service." Based on this act, the Indian health program was transferred from the Bureau of Indian Affairs (BIA) to the Indian Health Service, which became the major provider of Federal health services to American Indians and Alaska Natives. The 1975 Indian Self-Determination Act (Public Law 93-638) gave tribes the capability of contracting, as well as the options of staffing, managing, and controlling, their own health programs. These latter programs are commonly referred to as "93-638 contracts".

The National Indian Health Service (IHS) is charged with providing health and medical services to American Indians and Alaska Natives (predominately in the 33 reservation states). It also provides the central organizational focus for cancer prevention and control services in this hard-to-reach/access population. The IHS program consists of tribal and federally operated hospitals, clinics and health centers as well as an extensive contract health services component. The mission of IHS is to raise the health of Native Peoples to the highest possible level.

Perhaps because of these public laws, it has been erroneously assumed that the IHS has the sole responsibility of providing health care to all American Indians and Alaska Natives, either directly, or through P.L. 93-638 contracts. Although the IHS has the primary responsibility, it cannot accomplish its mission without collaboration with other federal agencies.

The Indian Health Service coordinates services through its 11 regional administrative units which are called IHS Area Offices. The Office of Health Program Research and Development in Tucson is also considered an Area Office even though it functions differently than the other 11 Areas. In the Fall of 1990, the Area Offices consisted of 136 service units, of which 58 were operated by tribes. As of 1990, tribes operated 7 hospitals, 89 health centers, 3 school health centers, 64 health stations, and 173 Alaska Village Clinics and the IHS operated 43 hospitals, 66 health centers, 4 school health centers, and 51 health stations. In addition to these health facilities, the IHS partially funds 34 urban Indian programs. Of these, 28 are medical clinics.<sup>6</sup> The 12 IHS Area Offices covering 33 reservation states are: Aberdeen, Alaska, Albuquerque, Bemidji, Billings, California, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson.

Although Indian Health Services are not limited to reservation-based Indians, the IHS clinical facilities are usually found on or near reservations and receive the majority of health funds. American Indians and Alaska Natives live in all fifty states, but the Indian Health Service provides services in the following 33 states which are designated "reservation states":

**Table 1.3 The 33 Reservation States**

Reservation States (33)		
Alabama	Maine	North Dakota
Alaska	Massachusetts	Oklahoma
Arizona	Michigan	Oregon
California	Minnesota	Pennsylvania
Colorado	Mississippi	Rhode Island
Connecticut	Montana	South Dakota
Florida	Nebraska	Texas
Idaho	Nevada	Utah
Iowa	New Mexico	Washington
Kansas	New York	Wisconsin
Louisiana	North Carolina	Wyoming

### **Survey of American Indians and Alaska Natives (SAIAN) - Access to Care Survey Items**

The National Medical Expenditure Survey (NMES) II Household Survey provides extensive information on health expenditures by or on behalf of American families and individuals, the financing of these expenditures, and each person's use of services. The NMES is a research project of the Center for General Health Services Intramural Research, Agency for Health Care Policy and Research. This same survey instrument was administered as the Survey of American Indians and Alaska Natives (SAIAN) and was implemented in 1987 to 6,500 individuals who lived on or near federally recognized reservations in 33 states. A multistage area probability sample design was used.<sup>18</sup> According to the SAIAN, persons who identified a facility not operated by the Indian Health Service as their usual source of care were more likely to have had an appointment, to have traveled shorter distances, and to have waited less time to be seen than those who reported using the Indian Health Services as their usual source of care.<sup>18</sup> Many IHS-eligible persons identified a facility not supported by the Indian Health Service as their usual source of care. This was found most often for those who had private health insurance or relatively higher income.

### **Urban American Indians and Health Services**

In 1976, Congress passed the Indian Health Care Improvement Act (Public Law 94-437) which addressed the health deficiencies of Indians living on reservations and in urban areas. Title V of this law, "Health Services for Urban Indians", is directed at improving the health status of urban Indians. In 1992 there were 34 urban Indian health programs in 19 states receiving Title V IHS funding and two additional programs in Oklahoma funded as "demonstration projects" under the IHS. Although 54-68 percent of the American Indians and Alaska Natives primarily reside in the urban areas, less than 2 percent of the total IHS budget is allocated to urban Indian clinics. As of December 1992, only one individual from IHS headquarters was assigned to urban health programs. The 34 urban Indian clinics which receive partial support from IHS are listed in Appendix A.

## DISCUSSION

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"Many challenges are facing American Indian and Alaska Native communities, and certainly one of the most important is their well-being: the health of their people, their cultural traditions and their environment. Many Indian people are rediscovering traditional perspectives that are relevant in addressing these challenges. The importance of balance in their lives, in their communities and with their environment is once again being seen as playing a vital part in the process of health promotion, disease prevention, and community development...The historical record is clear. No one can make Indian and Alaska Native communities do something they do not wish to do. It is Indian people who are ultimately responsible for their own communities, and it is Indian people who will determine what level of health Indian people will achieve and maintain." (Stanford Center for Research in Disease Prevention. *Restoring Balance: Community-directed Health Promotion for American Indians and Alaska Natives*. Stanford, California. (Library of Congress Catalog Card Number 92-93511) 1992, p. xiii.

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### Native Cultures

The health status of Native American groups cannot be fully understood apart from their history or their present social conditions. As with all other minority groups within the broad American population, poverty and education play major roles. Certainly, there have been many misconceptions about American Indians and Alaska Natives. All too often contemporary media carries news only of the disturbances and not the triumphs of Native American people. All too often the public perception is distorted, sometimes in a highly romanticized or very negative direction. It is time to reexamine these attitudes and to conduct new assessments of the factors at play in determining the health and life expectancy of these groups. The cultural information supplied here is relative to the issues that should be considered in developing sensitive and acceptable health education programs and research endeavors.

There are reasons to hope that Native Americans with their growing political expertise will be able, as other groups have, to develop and implement culturally acceptable social and health programs. The fact remains that today, the health, welfare and education of Native Peoples fall below the national average.<sup>5</sup>

Fortunately, progress has been made in some areas toward self-determination and independence. Many American Indians and Alaska Natives are currently participating in an empowerment movement with the goal of expressing themselves as stronger, confident, self-reliant Peoples proud of their beautiful and diverse cultures. In the 1930's through to the early 1960's, many Native People denied their heritage for fear of prejudice and other forms of alienation. However, since the latter 1960's, there has been a resurgence of American

Indian consciousness. At the present time, there is a strong "pride" in being recognized as Native American.

This shift from denying to acknowledging one's heritage and ancestry creates data problems for the researcher or program planner. For example, an individual may have self-identified himself as "Caucasian" on the 1980 U.S. Census, but as "American Indian" on the 1990 U.S. Census. The researcher or program planner who is attempting to utilize Census data has no way of determining if the individual is of high blood quantum which may be of interest if genetic cancers are the focus of one's research project. Likewise, the researcher or program planner does not know whether the individual practices Native American cultural behaviors or white cultural practices which influence health outcomes.

All cultures, whether it be Oglala Sioux, Italian, Cambodian, etc., have positive, respected practices that helped prevent disease and contributed to the well-being of the community in the past. When Native Americans attempt to learn Native languages, dances, songs, crafts and so on, it is to remember cultural practices that help contribute to a positive, balanced lifestyle. The desire is not to "give up" all modern conveniences and return to living in habitats that were used in the 1400's. It is to retain the beauty and harmony of the old ways.

### **Recommendations for Researchers Working With Native Communities**

Whenever possible, researchers and program planners are encouraged to stress positive behavioral change which can reduce the risks of cancer as well as cardiovascular disease, obesity, diabetes, and so on. The research project is likely to be perceived in a more positive manner by the Native group if the benefits to overall health of the Native community are taken into consideration rather than relating a research project to only one of several serious health concerns. For example, an educational intervention should stress that reducing dietary fat intake helps prevent certain types of cancer, cardiovascular disease and obesity..

A basic understanding of Native American cultures is required prior to developing a research project. From a public health perspective, it is critical to understand the cultural and behavioral diversity that exists among tribes, clans and bands of Indigenous Peoples. The goal of most cancer prevention and control research projects is to change behavior (e.g., participate in annual Pap smear screening examinations). Native American cancer interventions need to be culturally acceptable, sensitive, competent and relevant. The behavioral intervention needs to be integrated within the cultural context in these unique cultural mores.

Cultural perceptions are sometimes misinterpreted by some researchers and program planners. Whichever Native population group is the target for the research project, time needs to be invested to learn how these particular groups perceive their own cultures. Those perceptions may be incorporated within the research project. Acknowledgement of the history, perceptions, and sensitivities and an understanding of both the similarities and differences between Native Peoples and the broader American society will help in conducting effective research and creating useful health education programs.

The researcher or program planner needs to work closely with members of the target population to determine where and how local Native communities interact. For example, many contemporary Indigenous Peoples continue to practice tribal customs and participate in

numerous Native ceremonies, whether they live on a reservation, in a remote Alaska Native village or in an industrialized city. Some social functions, such as Pow Wows, (Pow Wows are gatherings that reinforce cultural social support systems and encourage Native People to sing, dance, and socialize) may be appropriate locations to implement recruitment efforts into a cancer education project for example.

Although over half of all Native People live in urban areas, moving to the city does not necessarily make someone less of an Indian, Aleut, or Eskimo. The disorientation some Native People experience when exposed to urban life may predispose them to adopting unhealthy behaviors, e.g., consuming alcohol or smoking cigarettes. However, other Natives choose to adopt mainstream practices that do not conflict with Native practices and beliefs while retaining traditional practices. For example, urban dwelling Native People who have retained their cultural beliefs typically engage in social events, such as Pow Wows. Often urban Indian people participate in "sweats" (prayer ceremonies in sweat lodges) or other types of healthful healing activities. An American Indian may be a member of a "Native Drum" and practice singing traditional songs to stay in touch both with oneself and one's culture. There are a variety of healthful and culturally acceptable behaviors that one may practice while living in the urban area.

Many successful research projects include Native traditional healers on the advisory boards to increase the likelihood that committee decisions will be acceptable to and representative of the local Native community. Such collaboration between traditional and Western medicine are likely to eliminate delays of the patient seeking appropriate medical treatment or follow-up screening.

Trading for goods and services continues to be a common practice among Native communities regardless of where the Native populations reside. Such trading practices have strengthened Native support systems. Occasionally trading practices have been integrated with research projects, such as a bag of wild rice may be "traded" for knowledge obtained by being interviewed for a cancer survey.

### **Cultural Similarities among Indigenous Peoples**

Although each surviving Native American tribe, clan, or band (terms used to describe Native American groups) has its own unique culture, there are some generalizations which are valid for most tribal communities. The majority of Native cultures live gently and respectfully within their environment. The Indian way is to live in harmony with the Earth and with oneself and to walk with spirit, heart, mind and body in balance as an integrated being. This concept of balance and relationship to Mother Earth, Father Sky, and all Beings extends to all aspects of life and living within the family.

#### ***Traditional Healing***

Traditional healing is still practiced and respected by most Native cultures. Traditional healing involves treating the body, mind, and spirit of the individual in addition to the symptoms and physical manifestations. Diseases which are regarded to be "white man's diseases" (e.g., diabetes or cancer) usually do not have traditional treatments since the diseases did not exist in sufficient numbers or were not recognized to warrant a treatment

until recent years. Traditional healers and medical doctors occasionally work cooperatively with one another, and are greeted with great welcome and relief by Native patients.

### *Social Structure*

Native cultures have strong social structures. The family is the focal point of most activities and practices. Within the family unit, the woman is highly esteemed because she gives the gift of life. The woman is typically the caretaker of the family who places the needs of family members before her own. Likewise, the male is traditionally viewed as the protector of the home and the local tribal community. Children are viewed as blessings from the Creator and are included in almost every tribal activity rather than being kept at home to be watched by non-family persons. Elders are cherished as resources of vast knowledge and experience; it is expected they will help educate the young about tribal practices, histories, and ceremonies which are verbally passed from one generation to another. Each of these family member roles can be constructively integrated within a cancer research project.

Although symbolism is common among Native People, specific symbols usually have different connotations among the different tribes. Circles, such as "the Circle of Life" and the "Medicine Wheel", have multiple positive meanings among tribal communities as do the Four Directions - East, South, West and North. Non-Natives should be cautious about using symbols because of the diversity of interpretation and connotations among tribes.

### **Demographic Considerations**

The researcher or program planner needs to be apprised of demographics while designing a cancer project. For example, it is inappropriate to plan to implement a telephone survey on the Navajo reservation where over 74.5 percent of the population do not have access to a telephone. Since the poverty rates are high, research projects which generate employment as well as train Indigenous Peoples in new fields and increase empowerment are more welcomed in tribal communities than are projects that send non-Natives to a reservation or Indigenous Health Clinic to implement the research project. The education level is low among many indigenous Peoples, which requires that research materials, such as statement of consent or intervention pamphlets, be written at a literacy level that most residents can understand. The previous description of demographics is a compilation of national data. Local Native data are different and require collaboration with Native communities to obtain accurate demographic information for the local target population. Such data are essential to identify appropriate cancer intervention settings and methodology.

### **SUMMARY**

This first section was an overview of American Indian and Alaska Native Peoples' present condition as well as a brief summary of background information. Although most people living in the U.S. are aware of Indigenous Peoples through movies and other media, their Hollywood image differs from their actual living situations. Descriptive information was provided which may complement cancer risk factors, incidence, mortality, and survival data which are further explained in subsequent chapters.

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## **CHAPTER 2: LIMITATIONS OF EXISTING CANCER DATA AMONG AMERICAN INDIANS AND ALASKA NATIVES**

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### **CHAPTER OBJECTIVES:**

- DESCRIBE THE LIMITATIONS OF NATIONAL CANCER DATABASES
  - IDENTIFY THE TYPES OF DATA WHICH NEED TO BE COLLECTED
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### **INTRODUCTION**

Policy makers, researchers, and health care professionals at all levels (federal, state and local) rely on national databases as accurate, representative sources of information. Existing national databases, such as the U.S. Census population counts, National Center for Health Statistics mortality data, National Cancer Institute Surveillance, Epidemiology, and End Results (SEER) Program, and National Indian Health Service, are cited as reputable sources for cancer information. However, each national cancer database has limitations when used for American Indians and Alaska Natives which need to be acknowledged when these data sources are utilized.

There is no single national database that accurately presents cancer-related data for Indigenous Peoples. As a result, multiple databases must be relied upon to assess the cancer problem among American Indians and Alaska Natives. The heterogeneity of American Indian and Alaska Native populations and their lifestyles has contributed to difficulties in drawing conclusions about the reported lower incidence of cancer in Indigenous Peoples than in other minority groups. This database limitation is not specific to American Indians and Alaska Natives, but affects most racial groups.

### **The Limitations of Regional and National Databases**

The types of cancer data that are available for U.S. whites and blacks are unavailable for the majority of Native Americans, Hispanics, Vietnamese, and so on. The diversity of American Indian populations greatly limits generalizing available cancer data to all tribal groups.

Based upon the limited data, cancer appears to be accelerating throughout Indian Country, and is worse in Alaska and the Northern states. Accurate data are needed to set health priorities and develop innovative cancer programs. Accurate statistics are critical for

epidemiologic research and for the design, implementation, and evaluation of public health interventions.<sup>1</sup>

Limitations of national databases which affect *most* underserved populations (e.g., Native Hawaiians, Vietnamese, Hispanic) include one or more of the following:

- Racial misclassification
- Undercounting
- Coding errors (universal to people of all races)
- Inclusion of insufficient numbers of the racial group to formulate conclusions
- Data collection in selected geographic regions which cannot be generalized to Peoples in other areas

The quality of databases varies among racial groups and among geographic regions of the country. For example, the data from the New Mexico Tumor Registry are among the more comprehensive and accurate records of cancer among American Indians and Alaska Natives. New Mexico Tumor Registry staff recognized the need to collect accurate and precise data on all people, including underserved populations, such as American Indians and Hispanics. As a result, data collection protocol was implemented which accurately ascertains the race and diagnosis of the cancer patient. Other tumor registries may not have had the same level of interest to incorporate similar techniques until recent years. Collection of accurate racial information is now a higher priority in tumor registries, such as the Fred Hutchinson Cancer Research Center.

## THE U.S. CENSUS DATA

DATA LIMITATIONS: (1) UNDERCOUNT OF AMERICAN INDIANS AND ALASKA NATIVES; AND (2) RACIAL/ANCESTRY SURVEY ITEMS.

The Census Bureau produces published and unpublished statistics from its censuses and surveys for states, counties, cities, etc. and from the decennial census, for smaller areas down to the size of a city block.<sup>2</sup> The results of enumeration of people and their housing units every ten years provides an overview of the population size and distribution, socioeconomic and housing characteristics.

The Census Bureau has been collecting information on American Indians as a separate group since 1860, but Indians living in Indian Territory and on reservations were not included in population counts until the 1890 Census.<sup>3</sup> In preparing for the 1990 Census, the Census Bureau established liaisons with more than 300 tribal governments in their attempt to include all American Indian and Alaska Native people in the Census. Among urban and rural dwelling Native Peoples, one in six households received the long questionnaire. However, on reservations and in Native Villages, although one in two households were to receive the long questionnaire, many households were excluded. The Census estimated that racial minorities were undercounted by approximately 6 percent in the 1980 Census. The estimated undercount of minorities in the 1990 Census was at least as high.

## **Undercount of Native Americans**

Many American Indians and Alaska Natives did not participate in the Census even though Census personnel made repeated attempts to contact them. Lack of Native participation by Native People was due to several reasons. Native People migrate from rural villages or reservations to the urban area to find employment. Jobs such as fire fighting in Washington, lumbering in Montana, and fishing in Alaska are seasonal and may require migration for several months at a time. Other Natives purposely did not participate in the Census in protest to a long history of broken U.S. governmental commitments and in recognition of their own Indian Nations' sovereignty.

## **The "Race" and "Ethnicity" survey items**

A major limitation of U.S. Census and other questionnaires is the question asking about "race". The resulting number of American Indians and Alaska Natives change depending on the phrasing of the question. For example, the U.S. Census racial question allows American Indians and Alaska Natives to identify their ancestry rather than requiring blood quantum or tribal enrollment numbers. Hahn (1992) states that there is an overcount of American Indians when self-identity or ancestry are used in Census data. In a 1980 re-interview study, 41 percent of persons who identified themselves as American Indian had reported themselves as white in the 1980 census. Also in the 1980 census, while an estimated 6.8 million persons reported American Indian ancestry, only 1.2 million reported American Indian race ... only 73 percent of those reporting American Indian race claimed American Indian ancestry".<sup>4</sup>

Blood quantum is not always a clear indication of American Indian Alaska Native status. For example, someone who has 1/16 of Native bloodline may mark American Indian or Alaska Native on the Census, but live in accordance with mainstream lifestyles. Many Native People fear that non-Natives who identify themselves as Indians will try to gain access to tribal benefits, such as health services and special educational programs. This also raises the unresolved issue that ancestry, cultural identity and blood quantum are frequently but erroneously used as equivalent indicators of racial status.

Tribal enrollment may also present confusion. People who are of mixed Indian blood may be enrolled in multiple tribes. When completing the U.S. Census questionnaire, the instructions specify that the principal tribe be listed first on the questionnaire. When interpreting and summarizing data, the Census only includes the first tribe listed in its analysis, losing important information about behaviors which may be inherent to "secondary" tribal affiliations. Misclassification of cultural and lifestyle behaviors occur when the individual is active in more than one tribe. Tribal behaviors are diverse and may have a significant impact on the presence or absence of cancer risk factors.

## **NCI SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS DATA (SEER)**

DATA LIMITATIONS: (1) MOST SEER TUMOR REGISTRIES HAVE RACIAL CLASSIFICATION ERRORS; AND (2) SOUTHWESTERN DATA CANNOT BE GENERALIZED TO NATIVE PEOPLES LIVING IN OTHER REGIONS.

The Surveillance, Epidemiology, and End Results (SEER) Program was initiated in 1973 by the National Cancer Institute (NCI) to collect cancer data on a routine basis from designated population-based cancer registries in various areas of the country. The geographic areas comprising the SEER Program's data base represent an estimated 9.6 percent of the United States population and include states or counties such as Connecticut; Detroit, Michigan; Iowa; New Mexico; Utah; San Francisco/Oakland, California; Hawaii; Atlanta, Georgia; and Seattle-Puget Sound, Washington.

The SEER program (1) provides estimates of cancer incidence and mortality in the United States; (2) monitors annual cancer incidence trends to identify unusual changes in specific forms of cancer occurring in population subgroups defined by geographic, demographic, and social characteristics; (3) provides continuing information on changes over time in the extent of disease at diagnosis, trends in therapy, and associated changes in patient survival; and (4) promotes studies designed to identify factors amenable to cancer control interventions, such as: a) environmental, occupational, socioeconomic, dietary, and health-related exposures; b) screening practices, early detection and treatment; and c) determinants of the length and quality of patient survival.

The SEER areas are responsible to record information from all death certificates on which cancer is listed as a cause of death for residents dying in or outside the coverage area. They also collect new cases and register malignant neoplasms with the exception of certain histologies for cancer of the skin. SEER records data on all newly diagnosed cancers, including selected patient demographics, primary site, morphology, diagnostic confirmation, extent of disease, and first course of cancer-directed therapy. SEER also provides active follow-up on all living patients except those with in situ cancer of the cervix uteri. This and other information is submitted to NCI twice a year. A quality control program has been implemented to ensure quality.

SEER registries are regarded as being among the best sources of cancer data. However, New Mexico is the only SEER site that contains a sufficient number of American Indians (19 percent of all Indian people live in Arizona and New Mexico) and represents a reasonable sample within its SEER population. These data are useful for local tribes that include, but are not limited to, the Navajo, Hopi, Mescalero Apache, Jicarilla Apache, Ute, Pascua Yaqui, and nineteen Pueblo tribes (e.g., Zuni, Acoma, Santo Domingo). However, given the uniqueness of different American Indian and Alaska Native tribes and clans, New Mexico data are not representative of the populations from other regions. This will be illustrated in Chapter four.

## **NATIONAL CENTER FOR HEALTH STATISTICS**

DATA LIMITATIONS: (1) INCLUDE INSUFFICIENT NUMBERS OF AMERICAN INDIANS AND ALASKA NATIVES ON NATIONAL SURVEYS SUCH AS THE NHIS; AND (2) RACIAL MISCLASSIFICATION.

The Centers for Disease Control and Prevention's National Center for Health Statistics has a variety of data including, but not limited to, mortality statistics, results from the National Health Interview Survey, and the National Death Index.

## National Health Interview Surveys

The National Center for Health Statistics (NCHS) is responsible for administering the National Health Interview Survey (NHIS) annually. This is one survey the Center uses to collect information on the health of civilian non-institutionalized Americans. The NHIS provides data on the incidence of acute illness and injuries, the prevalence of chronic conditions and impairments, the extent of disability, and the utilization of health care services by persons seventeen years of age and older. Data are collected during a 20-90 minute personal interview on a cross-sectional sample of households that are representative of the U.S. population, but not of individual states. Census interviewers collect information on approximately 46,500 households and 122,000 persons and generally maintain an annual response rate of 95 percent.

The two-part NHIS questionnaire includes a set of basic health and demographic items that are administered annually, and a supplemental survey of current health topics. The supplemental survey includes questions from several sources outside of NCHS. In the 1987 and 1992 Cancer Supplements, the National Cancer Institute submitted a section on cancer-related risk factors and an epidemiologic study questionnaire. The latter includes specific questions related to diet, screening examinations, and family history of cancer.

Population surveys conducted by NCHS have collected ample information on Caucasians, blacks, and Hispanics to begin to understand the variety of health issues affecting these populations. Since 1985, blacks have been over-sampled to improve the precision of estimates for the population. Hispanics were over-sampled for the 1992 survey. The Hispanic Health and Nutrition Examination Survey (HHANES, 1982-84) also included a section on cancer risks and collected information on several epidemiologic questions.

There have been insufficient numbers of Native Americans responding to the NHIS to draw any conclusions. For example, there were only 149 out of 22,043 (0.006 percent) American Indian and Alaska Native respondents 18 years and older who completed the Cancer Control Supplement in 1987 and 135 out of 22,080 (0.006 percent) American Indian and Alaska Native respondents in the Cancer Epidemiology Supplement. In 1990, there were 288 out of 41,104 (0.007 percent) American Indian and Alaska Native respondents included in the Health Promotion Disease Prevention Supplement (NCHS). These compare quite unfavorably with American Indian and Alaska Native representation in the U.S. population, which in 1980 was 1.4 million (0.6 percent) and in 1990 was 1.9 million (0.8 percent).<sup>5</sup>

## Mortality Data

Each state submits death certificates, void of personal identification, to the National Center for Health Statistics for inclusion in national mortality analyses. Submitted death records are based upon the information included on death certificates which is completed at the hospital or funeral home in the local level. Information to be included on the death certificate is provided by the attending family members to the funeral director, or whoever is completing the death information. Unfortunately, the funeral director may assume the race of the deceased individual rather than directly ask the bereaved family members this question. Racial misclassification on death certificates is the major cause of inaccurate national mortality statistics and the impact of misclassification is described in the following section.

## State Death Certificates

Mortality data are collected in the local area and then are transmitted to state and federal levels. When racial misclassification, diagnostic and recording errors occur on the local level, these data lead to misinformation in the state and national databases resulting in potentially erroneous conclusions. The accuracy of state tumor registries is totally dependent on the accuracy of local data which are submitted to the states. As a result, the accuracy of state databases is variable and inconsistent.

The most significant and common problem among state and national databases is racial misclassification. Racial information was eliminated from many types of documents including hospital records and tumor registries during the 1960's and 1970's. When racial information is requested on official forms, the attending health care provider or clerk frequently assumes the patient's race by visual observation rather than by asking the individual to identify one's race. This creates the situation of being born "American Indian" or "Alaska Native", but dying "white" or "Hispanic". Race is frequently misclassified on death certificates and the magnitude of these errors varies by state.

## STUDIES ON RACIAL CLASSIFICATION

Comparisons of birth and death certificates indicate that misclassification occurs at all ages. According to Patterson (1980), racial misclassification occurs at birth for one of two reasons. The first is the difference in the way in which race is determined from the birth and death certificates and the second reason is the possibility of errors in the reporting of the race of the parents on the birth certificate.<sup>6</sup> Similarly, Frost (1980) found that infants born to Indian fathers and white mothers were coded Indian at birth but were not coded Indian at death in 71 percent of the cases examined. Even with two Indian parents, 10 percent of infants were classified as a different race at death.<sup>7</sup> In a California study linking birth and death records between 1965 and 1967, 148 infants were coded American Indian on birth records but only 61 were coded American Indian on the death record.<sup>8</sup> In another study linking birth and death records in New York (excluding New York City) between 1973 and 1977, of 39 infants coded Indian at birth, only 25 infants were coded "American Indian" at death.<sup>7</sup>

Frost (1992) investigated the extent to which racial misclassification contributed to the observed low incidence of cancer among Indigenous Peoples by linking IHS service population with the Puget Sound Surveillance, Epidemiology, and End Results (SEER) cancer registry. Only 60 percent of the patients with invasive cancer registered with the IHS and for whom race was recorded, were identified as Native Americans in the SEER registry. In addition, only 69 percent of in situ cervical cancer case patients were correctly identified as Native American.<sup>9</sup> The observed low cancer incidence in Native Americans relative to whites in the northwest is at least partially attributable to racial misclassification in the SEER cancer registry.<sup>9</sup>

Hahn (1992) reviewed assumptions underlying federal health statistics on racial and ethnic groups in the United States and clarified several of the problems which accompany racial identify, self-reported race, and ancestry. The differences between self-reported racial identification and interviewers' classification differ among all races. For example, 32.2



percent of self-reported Asians and 70 percent of self-reported American Indians were classified as "white" or "black" by interviewers.<sup>4</sup> Hahn (1992) concluded that the quality of statistical information on the health of racial and ethnic populations in the United States is problematic. He suggested that better-quality information would enable more effective health research and program planning.<sup>4</sup>

Hahn and others (1993) recently examined racial classification from birth and death certificates from 1983-1985 for American Indian and Alaska Native infants in the 33 reservation states. Misclassification of race for American Indian and Alaska Native infants was 26 times greater than that of U.S. white infants (1.3 percent). Overall, misclassification of race on birth and death certificates for American Indian infants tended to occur about 50 percent of the time, although racial misclassification ranged from 100% in Massachusetts and Pennsylvania to less than 10 percent in Arizona and South Dakota. Hahn concluded that in general, reservations states with greater numbers and greater proportions of American Indian and Alaska Native births tended to have greater consistency of racial classification on birth and death certificates.<sup>1</sup> Hahn's conclusion, however, is not accurate for the two states which have the largest numbers of American Indians: Oklahoma and California. The percent of consistent race classification at death compared with birth records for Oklahoma was 48.6 and for California was only 19.3.<sup>1</sup>

Sugarman (1993) assessed the extent to which injury rates among American Indians in Oregon were underestimated owing to misclassification of race in a surveillance system. The data reported to the Oregon Injury Registry in 1989 and 1990 were examined. Race is reported to the registry by responding hospitals based on routine ascertainment according to each hospital's policy, which may include either patient self-report or observation by hospital staff. The Oregon registry was linked with the Indian Health Service database to confirm the race of the patient. The number of cases in the registry that were identified as American Indian in at least one of the data sets increased by 29.6 percent ( $n=390$ ) after the data linkage. Prior to data linkage, the injury rates among American Indians and Alaska Natives were substantially underestimated because of racial misclassification.<sup>10</sup>

### State Tumor Registries

New Mexico has the fourth largest American Indian and Alaska Native population and Arizona ranks third (Oklahoma and California are first and second respectively). The New Mexico Tumor Registry (NMTR) has collected data on all residents living in New Mexico since 1969. Because Arizona did not have a statewide cancer registry, the Indian Health Service (IHS) in 1969 asked the New Mexico Tumor Registry to include all Navajo Area IHS hospitals (including the ones in Arizona) and in 1980 IHS and NCI asked the NMTR to include the rest of the IHS facilities in Arizona.<sup>11</sup> This tumor registry has collaborated with IHS and has implemented a data linkage and abstractor training which has resulted in more accurate racial classification of patients. The procedures and protocol which have been utilized by the New Mexico Tumor Registry may be adopted by other tumor registries to reduce racial misclassification.

Racial misclassification has been recognized by other tumor registries which also include large numbers of American Indian and Alaska Native People. Washington State, which has the sixth largest Indigenous population in the U.S., has frequently misclassified Native

People as "white." Puget Sound (SEER) cancer registry in western Washington estimates 40% misclassification of American Indian and Alaska Native patients.<sup>9</sup> The Fred Hutchinson Cancer Research Center in Washington has been working with the Portland Indian Health Service to assist in correcting these errors. Racial misclassification in the Montana Central Tumor Registry was about 10%.<sup>12</sup>

### **The Effect of Racial Misclassification**

The effect of racial misclassification must be viewed as impacting on both the numerator (e.g., the number of cases) and the denominator (e.g., the population at risk); neither element can be ignored. The results of racial misclassification within the denominator may be over- or underestimation of the actual numbers of Indigenous Peoples which affects all statistical rates and ratios. The effects of misclassification of the numerator are underestimation of cancer incidence and mortality among American Indians and Alaska Natives and overestimation of cancer among whites, Hispanics, and occasionally black Americans. The underreporting of Native Americans on death certificates and other medical records results in the underreporting of cancer as a problem among Indigenous Peoples. As a consequence of underreporting, cancer among Indigenous People has not been given adequate attention as a health problem, it has not been a funding priority, it has not been thoroughly researched, and few culturally competent cancer prevention programs have been developed. Racial misclassification appears to vary within individual states mortality, incidence, and survival data.

### **INDIAN HEALTH SERVICE (IHS) DATA**

DATA LIMITATIONS: (1) LIMITED TO "USER POPULATION"; (2) ICD CODING ERRORS

Indian Health Service (IHS) databases include Native Americans who have used IHS services within the last three years. This population is called the "IHS user population." The IHS user population includes people who have documentation verifying their American Indian or Alaska Native descent or have a tribal enrollment number. American Indians and Alaska Natives are not included in the IHS database if they never use IHS facilities, have not used an IHS facility within the last three years, or use private practitioners or third party payment. Therefore, the IHS database only reflects a segment of the entire Native American population.

American Indians and Alaska Natives obtain health care from a variety of sources. In addition to IHS facilities, medical care is obtained from Indian owned-and-operated clinics and urban Indian clinics. Although the IHS partially funds both types of clinics, these clinics also receive funding from states, foundations, and a variety of fund-raising activities. Many American Indians and Alaska Natives have job-related medical benefits and use private practitioners and third party payment rather than IHS facilities. Contrary to many state health departments' efforts, American Indians and Alaska Native Peoples rarely utilize public health department medical facilities.<sup>13</sup>

Native Americans not living in the 33 reservation states must utilize alternative health resources or travel great distances to obtain services. For example, American Indian and

Alaska Native People who work for employers other than the federal government in the Washington, D.C. area must travel 400 miles one way to the nearest IHS facility in Cherokee, North Carolina. Native People employed by the federal government in the Washington D.C. area have access to medical insurance and therefore, do not usually utilize IHS services.

Over half of all American Indians and Alaska Natives live in urban areas and obtain health care from sources within the city. Those data are usually not provided to the IHS for inclusion in its database.

The major errors in the IHS databases are ICD coding of diagnosis. Valway (1992) found one IHS Area to have as many as 42 percent of 1000 medical charts to have coding of diagnosis errors (those IHS Area data are not included in this publication). The average coding error among IHS Areas is less than thirteen percent. The errors included incorrectly coded discharge diagnoses, coding diagnoses prior to obtaining laboratory test verification, and recording incorrect ICD codes. Many codes were for metastatic locations instead of primary cancer sites.

The Indian Health Service initiated corrective database review programs during 1992. Each Service Areas' database is scheduled to be reviewed and corrected, and if it is feasible, those data will be compared with state and regional tumor registries. The IHS plans to provide correct racial classification information to the state and regional tumor registries, and it is hoped that those registries will use this information to correct their state's databases.

## **URBAN AMERICAN INDIAN DATA**

DATA LIMITATIONS: (1) LITTLE TO NO CANCER SITE-SPECIFIC DATA COLLECTED; (2) ICD CODING ERRORS

The data on specific cancer sites and types; stage at diagnosis; frequency of cancer screening, diagnoses, treatment, and/or referral are not routinely collected or recorded according to consistent protocols in urban Indian clinics. The American Indian Health Care Association has analyzed urban mortality data for 1989 and 1991 that includes 9-year trend data (1979-1987) for the U.S. general population, IHS Service Areas and the urban Indian clinics for which data was available<sup>14</sup>. Cancer mortality rates remained fairly constant in both the general and IHS Service Area populations, but increased by 49 percent in the urban Indian populations, i.e., from 47.3 to 70.6 deaths per 100,000 population utilizing age-adjusted mortality rates. Much of the submitted data identifies cancer as the cause of death, but excludes the specific cancer site. Since various types of tumors respond differently to preventive efforts or treatment, tumor site specific data are needed from urban Indian clinics. Although the urban Indian clinics have been in existence since 1969, minimal information has been collected or published on cancer among urban dwellers.

The major limitations of data collected on urban Indians include inconsistent protocols used to report and record data, exclusion of data on Natives who migrate back and forth to reservations, and the failure to record ICD codes to identify specific cancer sites.

**TABLE 2.1 -- Summary: Purposes and Limitations of National Cancer Databases Related to American Indians and Alaska Natives**

DATABASE	PURPOSE OF DATABASE	LIMITATIONS
U.S. Census	To identify descriptive demographic information for all population units	<ul style="list-style-type: none"> <li>• Undercount of Native Americans</li> <li>• Racial misclassification</li> <li>• Insensitive to annual fluctuations</li> </ul> <p>Effects of limitations: affects accuracy of the data used as the denominator to generate rates, underestimates the number of American Indians and Alaska Natives and overcounts other racial groups</p>
Mortality Data (National Center for Health Statistics)	To identify the frequency of deaths by cause (based upon death certificate information provided by each state)	<ul style="list-style-type: none"> <li>• Racial misclassification</li> </ul> <p>Effects of limitation: undercounts of numerator data is likely to have greater impact in <u>under</u>estimating incidence and mortality rates in American Indian and Alaska Native populations with lesser impact of <u>over</u>estimating rates in the general population.</p>
Surveillance, Epidemiology, and End Results (NCI SEER Program)	To collect cancer incidence, and survival data on a routine basis from designated population-based cancer registries in various areas of the country; to analyze trends in cancer incidence, mortality (based on NCHS data), and patient survival in the United States	<ul style="list-style-type: none"> <li>• Racial misclassification</li> <li>• Most complete data are for Southwestern Indian tribes</li> </ul> <p>Effects of limitations: affects the accuracy of the numerator by underestimating the number of American Indians and Alaska Natives; Southwestern American Indian data are NOT generalizable to Indigenous Peoples from other regions of U.S.</p>

DATABASE	PURPOSE OF DATABASE	LIMITATIONS
Indian Health Service	To calculate IHS "user population" IHS patient care rates; IHS "user population" figures are used in calculating vital event rates since state birth and death certificates do not provide information on use of IHS services. <sup>15</sup>	<ul style="list-style-type: none"> <li>• Quality control related to medical records, e.g., data entry and coding of diagnosis</li> <li>• Limited to 33 reservations states</li> <li>• Partial and/or lack of urban American Indian and Alaska Native cancer data</li> <li>• Limited to its "user" population (i.e., used a facility within the last three years)</li> </ul> <p>Effect of Limitations: Data represent small portion of reservation American Indians and not the majority of the Indigenous populations.</p>

### THE NEED FOR QUALITY DATA

There is a paucity of data on the health status of American Indians and Alaska Natives which is useful for cancer prevention and control programs. These data are necessary for the development, implementation and assessment of innovative cancer prevention and control research interventions. These racial data need to be collected with increased emphasis on:

- Geographic regions, e.g., Alaska or the Northern Plains where cancer rates are significantly higher than for Native Peoples from other regions.
- Native communities exposed to cancer risks which are known to exist for non-Natives, e.g., Pine Ridge Reservation Indians subsisting on high fat commodities as their sole source of food (See Chapters 7 and 8).
- State tumor registries, particularly in states with a large (based upon the relative number in the U.S.) number or proportion of American Indians and Alaska Natives.
- Isolated Native communities in which the gene-pool has limited introduction of non-Native genes.

Tribal and Native community-specific data need to be collected by the local American Indian and Alaska Native groups rather than by federal agencies. Among the reasons why it is not practical for federal agencies and national databases include, but are not limited to the following:

- Lack of federal staff, protocols and equipment to collect, record and transfer such data to a national database.
- Total cost is prohibitive (considering effort versus outcome).
- Difficulties in accessing American Indians and Alaska Natives who live in urban areas unless they utilize one of the 34 urban Indian clinics.
- Difficulties in collecting information on American Indians and Alaska Natives who utilize third party payment.
- Cancer information is collected differently among urban Indian clinics, Indian-owned and operated clinics and IHS facilities (e.g., many do not use ICD codes and many do not include the cancer site or stage of diagnosis).
- Some tribes are very small, and rate calculates are subject to instability based on small denominators.
- Difficulties in accessing some tribal communities because of tribal politics, migratory lifestyles.

Information is needed on the 500 plus federally recognized tribes, hundreds of state-recognized tribes, urban Indian clinics, American Indian owned and operated clinics and IHS facilities, and local Native communities. Data are essential to initiate efforts to accurately record cancer incidence, mortality, survival and site data among Native Peoples. Federal and state governments may support local Native American organizations and communities in the development and implementation of culturally acceptable data collection techniques which utilize a common protocol for collecting and recording cancer data (e.g., the use of ICD codes).

### **Federal Agencies Acknowledgement of the Database Limitations**

During the last few years, federal agencies have sponsored reports, studies and/or meetings with Native Americans regarding data quality issues. The consensus from each of these independent meetings and reports has been that national data bases do not provide adequate information on American Indian and Alaska Native populations. Examples of these meetings and/or reports are provided below.

- The National Center for Health Statistics contracted with the American Indian Health Care Association to provide a report on data needs (December 1992)<sup>16</sup>
- The Network for Cancer Control Research among American Indian and Alaska Native Populations formulated a "*National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives*" which identifies national database limitations (October 1992)<sup>17</sup>
- The National Cancer Institute supported a meeting entitled "Native American Training Opportunities: Strategies for the Future" (August 31-September 1, 1992)

- The National Heart, Lung, and Blood Institute supported, "Minority Health Issues for an Emerging Majority: the 4th National Forum on Cardiovascular Health, Pulmonary Disorders, and Blood Resources" (June 1992)
- The Health Resources and Services Administration, Bureau of Health Resources Development, sponsored a, "Native American/Alaska Native Work Group on Barriers to HIV Care" (April 1992)
- The Centers of Disease Control and the AMC Cancer Research Center sponsored a training meeting for the twelve states who have received funds under the Breast and Cervical Cancer Mortality Prevention Act of 1990 (March 1992)
- The Agency for Health Care Policy and Research sponsored four regional meetings with racial and ethnic minorities (first quarter of 1992)
- The National Center for Health Statistics held a meeting in Bethesda, Maryland, "Setting a Research Agenda: Challenges for the Minority Health Statistics Grants Program" (December 1991)<sup>18</sup>
- California Department of Health Services Health Promotion Section offered a "Multi-ethnic Health Promotion Conference" (June 1991)<sup>19</sup>

The consensus from these as well as other meetings is that there is a need for collecting accurate data and developing culturally competent, acceptable and appropriate survey instruments, materials, and methodologies for minority and underserved populations. No established guidelines or protocols have been developed, however.

## SUMMARY

This chapter reviewed the purposes and limitations of selected national databases and the effects of the limitations on cancer among American Indians and Alaska Natives.

Researchers utilizing statistical information on the cancer problems among American Indians and Alaska Natives need to be aware of the limitations of the existing databases. The most accurate cancer data are from the New Mexico region, but these data are not generalizable to Native Peoples of other tribal affiliations and regions because of the diversity of lifestyles among Indigenous Peoples.

The limitations of selected national databases are described to substantiate the need for urban Indian clinics, Native-owned-and-operated health clinics, and IHS facilities to collect current and accurate information regarding their local service populations and to justify the need to utilize a standardized protocol for collecting and recording such data (e.g., the use of ICD codes).

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# CHAPTER 3: CANCER INCIDENCE, MORTALITY, AND SURVIVAL

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## CHAPTER OBJECTIVES:

- EXPLAIN HOW TO INTERPRET INCIDENCE AND MORTALITY DATA FROM STATISTICAL TABLES.
  - EXPLAIN HOW TO INTERPRET SURVIVAL DATA
  - COMPARE CANCER INCIDENCE, MORTALITY, AND SURVIVAL DATA AMONG AMERICAN INDIANS, ALASKA NATIVES AND WHITES.
  - IDENTIFY THE FIVE LEADING CANCER INCIDENCE AND MORTALITY SITES FOR AMERICAN INDIANS AND ALASKA NATIVES.
  - IDENTIFY FIVE CANCER SITES OF POOREST SURVIVAL AMONG AMERICAN INDIANS.
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## INTRODUCTION

With the limitations of national databases, a brief description of cancer incidence, mortality, and survival data is presented for American Indian and Alaska Native People. Native data are compared with white data and the leading cancer sites within each Native population are also listed. Although the data are accurate for only limited regions of the country, they are the best information available at this time. These data provide very broad generalizations for tribal and/or urban Indigenous populations.

## A REVIEW OF HOW TO INTERPRET STATISTICAL DATA

Sections are included in this chapter which review the interpretation of statistical data. There are a variety of statistics books available which provide depth and clarity for a comprehensive explanation. The reader is referred to *Cancer Statistics Review: 1973-1989* (1992) for a clear description of how the NCI SEER program calculates rates.<sup>1</sup> Colton's *Statistics in Medicine*<sup>2</sup> (1974) is another good source as are many other medical epidemiology texts.

## Adjusted Rates per 100,000 Population

When data are collected from different areas or from different periods of time, the populations may also differ substantially. The *crude annual death rate* is the simplest of the mortality rates and is defined as the total deaths during the year divided by the total midyear population. To avoid many decimal places, it is customary to multiply death rates by 100,000

and express the results as death per 100,000 population.<sup>2</sup>

It is difficult to compare crude rates among different populations, regions, and tribes because basic characteristics of the populations may also differ substantially, particularly with regard to age. Rates are *adjusted* to allow for comparisons, such as among racial groups or between sexes. Rates are adjusted through either the *direct* or *indirect* method.<sup>2</sup>

The data presented in this chapter include age-adjusted rates by the direct method. The purpose in calculating an "age-adjusted rate" is to remove the effect of the age differential so a meaningful comparison of cancer morbidity and mortality between populations is possible. For example, if the Indigenous population of the northeast were much older than the Indigenous population of the southeast, crude (unadjusted) cancer rates among northeastern tribes would indicate a more serious cancer problem than in the southeast since cancer is primarily a disease of older people. However, age-adjusted rates allow for the comparison of cancer morbidity or mortality data between northeastern and southeastern tribes as though the age distributions were comparable.

The "age-adjusted rate" calculation requires that the data of interest, such as the 1983-1987 lung cancer mortality crude rates, be compared with a standard population. Most national databases use 1970 U.S. population as the standard. The 1970 U.S. population is used as a standard set of the proportion of males and females in each age group. As long as each database uses the same group as the standard, e.g., 1970 population, those age-adjusted rates may be compared. This comparison is not possible if one database used the 1940 population as a standard and another database used the 1970 population as a standard. This does *not* mean that the rates generated in statistical tables are for 1970. The phrase "1970 U.S. Standard" apprises the reader of which population was used as the "standard" in the age-adjusted calculation. (See reference #2, p. 49, for detail)

### How to Interpret Incidence or Mortality Data from Statistical Tables

**Table 3.1** Excerpt from Annual Age-adjusted (1970 U.S. Standard) Cancer Incidence Rates per 100,000 Population, New Mexico only, 1977-1983.\*

	BOTH SEXES		MALE		FEMALE	
	No. <sup>3</sup>	Rate <sup>4</sup>	No. <sup>3</sup>	Rate <sup>4</sup>	No. <sup>3</sup>	Rate <sup>4</sup>
Stomach						
American Indian	164	17.6	97	22.3	67	13.8
White	310	8.9	187	13.3	123	5.8
Gallbladder						
American Indian	99	10.9	27	6.4	72	14.7
White	52	1.3	16	0.9	36	1.6
Cervix uteri						
American Indian	120	10.2	---	---	120	20.5
White	248	4.3	---	---	248	8.6

\* The data in this table for whites are from the state of New Mexico only. Data on American Indians from the state of Arizona have been added to those of New Mexico.

The *number* ("No.") is the actual number of diagnosed cases of cancer. The *rate* is the number of cancer diagnoses per 100,000 people of that population which occurred during one year. Using the data in this chart, one can compare the incidence rates of American Indians and whites for each cancer site. For example, review the stomach cancer incidence data for "both sexes". It is apparent that whites have a higher number of stomach cancer cases ( $n = 310$ ) than American Indians ( $n = 164$ ), but this is to be expected because of the difference in the numbers of people at risk. However, the rate is indicative of the risk of developing a case of stomach cancer. The white rate for both sexes is 8.9 as compared to the American Indian rate of 17.6 (i.e., for American Indians and Alaska Natives, more cancer cases occurred among fewer people than for whites). This means that American Indians are about 1.9 times ( $17.6 \div 8.9 = 1.9$ ) more likely to develop stomach cancer than are whites.

As a second example, review the data for gallbladder cancer incidence. American Indians have higher numbers and rates for cancer. Once again the "rate" information is more useful. The rate of developing a case of gallbladder cancer (both sexes) among American Indians is 10.9 as compared to only 1.3 for whites. Gallbladder cancer is 8.38 times ( $10.9 \div 1.3 = 8.38$ ) more likely to occur in American Indians than in whites. As the rates for each sex are examined, it becomes clear that females are at greater risk than are males, regardless of race. For example, American Indian males have a rate of 6.4 as compared to 14.7 for Native females which means that American Indian females are 2.29 ( $14.7 \div 6.4 = 2.29$ ) times more likely to develop gallbladder cancer than are American Indian males. A similar, but much less striking difference exists among whites, with white females being 1.7 times more likely to develop gallbladder cancer than are white males.

As a third example, review the data for cervical cancer under the "female" column. American Indian women have 2.3 times ( $20.5 \div 8.6 = 2.3$ ) the incidence of cervical cancer as compared to white females. Please note that even though cervical cancer is only possible to exist in females, rates for "both sexes" is typically included in tables. Obviously the sex-specific data are more accurate than data for both sexes where sex-specific diseases are concerned, e.g., male data for prostate cancer and female data for ovarian cancer.

### Interpretation of Appendices "B" and "D"

Appendices "B" and "D" include age-adjusted (1970 Standard) cancer incidence and mortality rates per 100,000 population by race and cancer site, 1977-83. These tables include cancer incidence and mortality rates to allow for comparisons among racial groups. The rates which are **redlined** indicate the highest rate of any racial group.

### CANCER INCIDENCE

Tables of average annual age-adjusted (1970 U.S. population) cancer incidence rates per 100,000 population by race, cancer sites, and sex are included in Appendix B.

"Incidence" refers to the number of *new* cases of a disease per persons at risk during a given time period. Thus, the denominator includes both persons and time. Alaska Native cancer rates typically exceed American Indian and occasionally exceed white rates. Although American Indians would also seem to be a high-risk group on the basis of socioeconomic status (SES), when compared with other racial groups, the incidence of cancer among American Indians is low. The incidence rate for all cancer sites combined for both sexes is less

than one-half that of whites, i.e., 157.3 per 100,000 person years, compared to the white rate of 359.2. It is not known if that comparatively low rate is (1) due to racial misclassification resulting from undercounting American Indians on health records; (2) reflective of cancer rates among Southwestern Indians which are not generalizable to Alaska Natives and American Indians from other regions of the U.S.; or, (3) an accurate assessment of cancer rates.

Alaska Natives have the highest cancer incidence rates among any racial group for the following sites: oral cavity and pharynx, colon and rectum, cervix uteri, and kidney and pelvis. (Data are based on SEER data for the State of Alaska only).<sup>4</sup> Alaska Natives have excessive incidence of cancers of the esophagus, stomach, liver, gallbladder, and pancreas.

According to the New Mexico Tumor Registry SEER data, American Indians who live in New Mexico and Arizona have excessive incidence rates for stomach, cervix uteri, liver, and gallbladder cancer. American Indians have the highest gallbladder cancer incidence rate (10.9) of any racial group, such as blacks, whites, or Hispanics.<sup>4</sup>

The following table is an excerpt from the NCI, *Report of the Special Action Committee: 1992*.<sup>4</sup> The complete table which includes data for racial groups is included in Appendices "B". The following table lists the cancer incidence rates in descending order for cancer sites of highest incidence among Alaska Natives. The second column is Alaska Native incidence rates for both sexes (using 1969-83 incidence data from the State of Alaska). The third column is for whites based on San Francisco-Oakland, Atlanta, Detroit, and Connecticut SEER data. The fourth column is American Indians living in New Mexico or Arizona. The asterisk identifies the highest (i.e., worst) rate for cancer incidence of any racial group (e.g., blacks, Hispanic).

**Table 3.2** Age-Adjusted (1970 U.S. Standard) Cancer Incidence Rates per 100,000 Population by Cancer Site, Both Sexes, for Alaska Natives (1969-83), American Indians and Whites, 1977-83<sup>4</sup>

Cancer Site	Alaska Native <sup>1</sup>	White <sup>2</sup>	American Indian <sup>3</sup>
Colon/rectum	*62.6	52.8	10.2
Lung/bronchus	46.9	56.2	7.3
Breast <sup>4</sup>	44.2	93.3	21.7
Prostate Gland <sup>5</sup>	34.5	73.6	37.6
Cervix Uteri <sup>4</sup>	*28.0	8.6	20.5
Oral Cavity/Pharynx	*16.5	11.7	2.1
Stomach	15.5	8.9	17.6
Kidney & Renal Pelvis	*11.2	7.2	7.5
Gallbladder	10.6	1.3	*10.9

## FOOTNOTES

- \* Indicates the highest rate for cancer incidence of any racial group (e.g., blacks, Hispanic, white)
- 1 Using State of Alaska, 1969-83 (based on data from Lanier and Knutson, 1986)
- 2 Using San Francisco-Oakland, Atlanta, Detroit, Connecticut SEER data
- 3 Using New Mexico Tumor Registry SEER data only; includes American Indians from Arizona and New Mexico only
- 4 Female data only
- 5 Male data only

The American Indian data from the New Mexico Tumor Registry provide an excellent overview of cancer incidence for Indigenous Peoples living in Arizona and New Mexico. However, according to NCI supported research projects implemented by the Indian Health Service (IHS), cancer incidence rates among different IHS Areas varied significantly for specific cancer sites. Examples of IHS age-adjusted incidence data (age adjusted to 1970 U.S. Population) from 1982-1987 follow:<sup>5</sup>

Lung Cancer Incidence Rates	Females	Males
SEER Whites	36.3	82.5
Billings IHS Area	37.8	56.4
Alaska IHS Area	58.4	85.2
Bemidji IHS Area	52.3	42.3

Bemidji = Michigan/Minnesota/Wisconsin

Aberdeen = Iowa/Nebraska/North Dakota/South Dakota

Billings = Montana/Wyoming

A brief review of the previous data clearly illustrates the variability of lung cancer incidence rates among IHS Areas. A few selected cancer sites are described in Chapter Four to more fully explain the regional and/or tribal cancer incidence and mortality rate variations.

#### Five Leading Cancer Incidence Sites within American Indian and Alaska Native Peoples

Table 3.2 compared Indigenous Peoples with non-Natives. The following tables illustrate the five leading cancer sites within American Indian and Alaska Native Peoples.

**Table 3.3** Five Leading Age-Adjusted (1970 U.S. Standard) Cancer Incidence Rates per 100,000 Population, 1977-83, among American Indians, New Mexico and Arizona Only<sup>4</sup>

American Indian Both Sexes		American Indian Female		American Indian Male	
Prostate gland <sup>1</sup>	37.6	Breast	21.7	Prostate gland	37.6
Breast <sup>2</sup>	21.7	Cervix uteri	20.5	Stomach	22.3
Cervix uteri <sup>2</sup>	20.5	Gallbladder	14.7	Colon/rectum	10.6
Stomach	17.6	Stomach	13.8	Lung/bronchus	10.5
Colon/rectum	10.2	Colon/rectum	10.0	Kidney/pelvis	8.1

#### FOOTNOTES

1 includes male data only

2 includes female data only

Even though breast cancer incidence rates are significantly lower among American Indian than in white women, it is the leading cancer incidence site among American Indian women living in Arizona and New Mexico. Likewise, prostate gland incidence among American Indians is significantly low when compared with whites or blacks, but it is the highest incidence site for American Indian males.



**Table 3.4** Five Leading Age-Adjusted (1970 U.S. Standard) Cancer Incidence Rates per 100,000 Population, among Alaska Natives, 1977-83, Alaska<sup>6</sup>

Alaska Native Both Sexes		Alaska Native Female		Alaska Native Male	
Colon/rectum	62.6	Colon/rectum	65.2	Lung/bronchus	69.7
Lung/bronchus	46.9	Breast	44.2	Colon/rectum	61.0
Breast <sup>1</sup>	44.2	Cervix uteri	28.0	Prostate gland	34.5
Prostate gland <sup>2</sup>	34.5	Lung/bronchus	23.2	Stomach	22.4
Cervix uteri <sup>1</sup>	28.0	Oral Cavity/pharynx	15.7	Oral cavity/pharynx	17.2

<sup>1</sup> includes female data only<sup>2</sup> includes male data only

Colon and rectum cancer incidence is elevated among both sexes. The lung cancer incidence is much higher among Alaska Native males than females.

## MORTALITY RATES

Tables which list average annual age-adjusted (1970 U.S. population) cancer mortality rates per 100,000 population, by race, cancer site and sex are included in Appendix "C". According to the National Center for Health Statistics, American Indians are experiencing excessive mortality rates for cervical, stomach, and gallbladder cancers when compared with whites. Alaska Natives have excessive mortality from cancers of the cervix uteri, colon and rectum, esophagus, gallbladder, kidney, nasopharynx, and salivary glands when compared with whites. The age-adjusted cancer death rates for the Alaska Area IHS (156/100,000) exceed those of the U.S. (132/100,000).<sup>6</sup> Colorectal, breast, and cervical cancers are the most frequent causes of death among Alaska Native women (cardiovascular disease is the leading cause of death for white women); stomach cancer is excessive for Alaska Native males. Alaska Natives have the highest mortality rates of any other racial group for cancers of the oral cavity, colon and rectum, gallbladder, corpus uteri, and kidney system.

The rates are based on death certificates, coded with cause of death, provided to NCI annually by the National Center for Health Statistics. As was described in the previous chapter, the attending health care provider may assume the race and records a code for a race other than American Indian or Alaska Native which results in undercounting the number of Indigenous Peoples who die of cancer.

As shown in the following table, cancer mortality sites are high in Alaska Natives in comparison to white rates. American Indian mortality rates remain low in comparison to these two groups. The asterisk indicates the highest (i.e., worst) cancer mortality rate of any racial group.

**Table 3.5** Age-Adjusted (1970 U.S. Standard) Cancer Mortality Rates per 100,000 Population by Cancer Site, Both Sexes, for American Indians, Alaska Natives and Whites, 1977-83<sup>4</sup>

Cancer Site	Alaska Native <sup>1</sup>	White <sup>2</sup>	American Indian <sup>2</sup>
Lung/bronchus	40.1	41.5	18.1
Colon/rectum	*24.6	21.3	9.0
Breast <sup>3</sup>	12.8	26.7	9.0
Cervix Uteri <sup>3</sup>	*12.5	3.2	5.5
Stomach	11.9	5.2	5.8
Pancreas	9.7	8.3	4.6
Liver	9.0	1.9	2.0
Oral cavity/pharynx	*8.3	3.3	1.8
Kidney & renal pelvis	*5.5	3.2	2.7

## FOOTNOTES

- \* Indicates the highest cancer mortality rate of any racial group (e.g., blacks, Hispanic, white)
- 1 Using State of Alaska, 1969-83
- 2 United States death certificate data
- 3 Female data only

Alaska Native mortality rates are similar or exceed the white rates. Alaska Natives have the highest mortality rate of any race for cancer of the colon and rectum, cervix uteri, oral cavity and pharynx, and kidney pelvis.

Based upon NCHS U.S. mortality data, American Indians have lower cancer mortality rates when compared with whites. The geographic regional data presented in chapter Four indicate that these mortality rates vary significantly among American Indians living in different areas of the country, such as the Northern States and Plains Indians.

#### Five Leading Cancer Mortality Sites among American Indian Alaska Native Peoples

Table 3.5 displayed cancer data by comparing Indigenous Peoples with non-Natives. The following tables illustrate the cancer sites having the highest mortality rates within Indigenous Populations.

**Table 3.6** Five Leading Age-Adjusted (1970 U.S. Standard) Cancer Mortality Rates per 100,000 Population, 1977-83, among American Indians, NCHS United States Data<sup>4</sup>

American Indian Both Sexes		American Indian Female		American Indian Male	
Lung/bronchus	18.1	Lung/bronchus	9.3	Lung/bronchus	28.8
Prostate gland <sup>1</sup>	11.8	Breast	9.0	Prostate	11.8
Breast <sup>2</sup>	9.0	Colon/rectum	8.0	Colon/rectum	10.1
Colon/rectum	9.0	Cervix uteri	5.5	Stomach	7.6
Stomach	5.8	Stomach	4.3	Pancreas	5.3

## FOOTNOTES

<sup>1</sup> includes male data only<sup>2</sup> includes female data only

Regional mortality rates appear to be much higher than those summarized in Table 3.6. For example, the Indian Health Service compiled cancer mortality data from their twelve Service Areas for the years 1984-88. States within three of the IHS Service Areas had extreme data problems due to the underreporting of "American Indian" on death certificates. Those three IHS Areas include the following states: Oklahoma, California, Washington, Oregon and Idaho. Data from those states and likewise their respective IHS Areas are not included in the following table.

**Table 3.7** Five Leading Age-Adjusted (1970 U.S. Standard) Cancer Mortality Rates per 100,000 Population, among Nine Indian Health Service Areas, 1984-88, IHS Data<sup>7</sup>

American Indian Both Sexes		American Indian Female		American Indian Male	
Lung	32.7	Lung	27.2	Lung	38.5
<i>Ill-def./unk.</i> <sup>1</sup>	16.9	<i>Ill-def./unk.</i> <sup>1</sup>	18.3	Prostate	15.8
Colon/rectum	11.2	Breast	16.1	<i>Ill-def./unk.</i> <sup>1</sup>	15.5
Stomach	9.9	Colon/rectum	11.8	Stomach	11.0
Breast <sup>2</sup>	8.4	Cervix uteri	10.0	Colon/rectum	10.6

<sup>1</sup> "Ill-defined/unknown" = unspecified in which organ cancer originated (ICD codes 159.1, 195.0-195.8, 196.1-196.9, 199.0-199.1, 202.3, 202.5-202.6)

<sup>2</sup> includes female data only

The previous two tables include rates which are quite different from one another. The cancer mortality rates are higher in the nine IHS Areas. Of marked increase is cancer of the lung, breast, and cervix. The "Ill-defined/unknown" are cancers for which the original cancer site is unknown (ICD codes 159.1, 195.0-195.8, 196.1-196.9, 199.0-199.1, 202.3, 202.5-202.6).<sup>7</sup> The high number of deaths from cancer with unknown original site are probably due to Native People living in remote areas with limited access to modern health care facilities.

The IHS data do not have racial classification problems. The differences in mortality rates published by the two databases may be due to the undercounting of American Indians on mortality data which are submitted to the National Center for Health Statistics.

**Table 3.8** Five Leading Age-Adjusted (1970 U.S. Standard) Cancer Mortality Rates per 100,000 among Alaska Natives, 1969-83, Alaska<sup>6</sup>

Alaska Native Both Sexes		Alaska Native Female		Alaska Native Male	
Lung/bronchus	40.1	Colon/rectum	27.2	Lung/bronchus	64.9
Colon/rectum	24.6	Lung/bronchus	15.0	Colon/rectum	22.1
Breast <sup>1</sup>	12.8	Breast	12.8	Stomach	17.2
Cervix uteri <sup>1</sup>	12.5	Cervix uteri	12.5	Liver	15.2
Stomach	11.9	Pancreas	10.3	Prostate gland	11.4

**FOOTNOTES**

1 includes female data only

Alaska Native mortality rates are higher than American Indian rates. Likewise, Alaska Native male rates are not similar to white male rates for lung cancer (64.9) but are similar for colon and rectum (22.1). The Alaska Native male rates are significantly higher than white male rates for stomach (17.2), and liver cancer (15.2).

## **FIVE-YEAR RELATIVE SURVIVAL DATA**

### **How to Interpret Survival Data**

The first section of this chapter described how to interpret incidence or mortality data. Survival data are interpreted differently than are incidence or mortality rates. Survival data are presented as the percentage of patients remaining alive five years after diagnosis. The *relative survival rate* compares the observed survival for a set of cancer patients to that observed for a group of normal persons of a similar age, race, and sex distribution. This mathematically 'adjusts' for non-cancer causes of death such as accidents, heart disease, and others. It is important to note that relative survival does not provide an estimate of the percent of the cancer patient population alive five years after diagnosis.<sup>3</sup>

### **Alaska Native Survival Data**

Survival data for Alaska Natives are in the process of being collected. An Alaska Native Tumor Registry collected data from 1969 to 1983 but due to the low number of cancer cases (less than 100 per year) the Registry lost its funding for several years. The Alaska Native Tumor Registry was reestablished in 1989 and is in the process of collecting information on incidence, follow-up, stage at diagnosis, and treatment. It will be several years before information is available from this registry.<sup>3</sup>

### American Indian Survival Data

The survival data for specific sites are listed in Appendix "D". Survival data are based on American Indian residents in the States of New Mexico and Arizona only. According to the data in Table 3.9, American Indians are less likely to be alive five years after diagnosis than are whites. The asterisk identifies the poorest survival reported for any racial group, including Hispanics, Blacks. The following table summarizes survival data for American Indians and whites.

**Table 3.9** Five-Year Cancer Relative Survival (%) for Both Sexes, American Indians and Whites, Cancer Site, 1975-84<sup>4</sup>

Cancer Site	American Indian <sup>1</sup> Both Sexes	White <sup>2</sup> Both Sexes
All Sites	*35.2	50.3
Gallbladder	*5.6	9.4
Stomach	*7.9	16.5
Lung & bronchus	*8.9	13.8
Non-Hodgkin's lymphoma	*33.5	50.5
Colon & rectum	*38.0	53.1
Kidney & renal pelvis	*38.1	51.9
Ovary <sup>3</sup>	47.2	*38.2
Breast <sup>3</sup>	*48.8	75.7
Prostate <sup>4</sup>	*51.4	69.8
Cervix Uteri <sup>3</sup>	65.1	67.2

#### FOOTNOTES

- \* Indicates the lowest percentage for cancer survival of any racial group (e.g., blacks, Hispanic, white)
- 1 Using New Mexico SEER data only; includes American Indians from Arizona and New Mexico only
- 2 Using SEER data from San Francisco-Oakland, Atlanta, Detroit, Connecticut
- 3 Female data only
- 4 Male data only

According to the data in this table, American Indians have the poorest survival rates *of any racial group* for every cancer site included in the table, except ovary and cervix.

### Five Cancer Sites of Poorest Survival among American Indians

The following table summarizes the five cancer sites which have the poorest survival among American Indians. Similar data are not available for Alaska Natives.

**Table 3.10** Five-Year Relative Survival (%) of American Indians from Selected Cancers, 1975-1984, New Mexico and Arizona Only<sup>4</sup>

American Indian Both Sexes		American Indian Female		American Indian Male	
Pancreas	0.0	Pancreas	0.0	Pancreas	0.0
Liver	0.0	Gallbladder	6.4	Gallbladder	3.0
Gallbladder	5.6	Stomach	12.0	Stomach	4.7
Stomach	7.9	Lung/bronchus	14.1	Lung/bronchus	5.8
Lung/bronchus	8.9	Leukemia	31.8	Leukemia	12.6

The zero survival from pancreatic cancer is true for people of all races. In about one-half of the diagnosed cases of pancreatic cancer, the cancer has already spread to other organs. This results in an overall five-year survival rate of just 3.2 percent for all races. Little improvement has been seen in five-year relative survival for liver cancer since the mid-1970's. The overall five-year relative survival rate for stomach cancer in all races is only 17 percent, but improves to 55 percent for cancers detected at the localized stage.<sup>1</sup>

## DISCUSSION

### American Indian Survival Data

A common misconception among Indigenous Peoples is that a cancer diagnosis is a death sentence. The data on the previous table suggest that experience underlies this attitude. The poor cancer survival among American Indians are partially due to the cancers being diagnosed in late stages of the disease. The earlier cancer is diagnosed, the more likely it is that treatment will be effective. This is particularly true for cancer sites such as cervix, colon and rectum and breast. For cancer sites such as lung, early detection is less effective and the disease often goes undetected until it has spread widely. Prevention through efforts such as smoking cessation is the most effective way to reduce lung cancer deaths.

There are more and more American Indian cancer survivors. In the recent past, Indian patients and their families experienced their disease in silence. The latter 1980's and early 1990's have been marked with the emergence of cancer activist groups, like "Living with Cancer". Such groups have been active within the white community for some time, but only rarely available in Indian Country. American Indian cancer survivors have independently organized and implemented cancer survival support groups within local Native communities. Among the many positive effects of such groups is that Indigenous Peoples' survival from cancer encourages others who have delayed seeking screening, diagnosis or treatment services to take care of themselves.

Cancer survival can be improved through patient compliance with screening and early detection services as well as seeking the recommended follow-up tests and/or treatment when test results are abnormal. Most abnormal test results are "precancerous", and indicate that

the cells in their present state are not cancerous, but that they are changing and are likely to develop into cancer if they are not treated as soon as possible.

Poor cancer survival may also related to lack of access to state-of-the-art screening and treatment services. Such services are available through National Cancer Institute sponsored clinical trials which are implemented in geographically diverse regions of the country. Specific eligibility criteria exist for any clinical trial, but people of all races are encouraged to participate. For further information regarding clinical trials or state-of-the-art treatment, the reader is referred to NCI's toll free telephone number (1-800-4-CANCER, or 1-800-422-6237).

## SUMMARY

This chapter provided a brief summary of American Indian and Alaska Native cancer incidence, mortality, and survival data. Data were age-adjusted to 1970 population to allow for comparisons with whites, as well as comparisons among Indigenous Peoples.

Incidence and survival data presented in this chapter are limited to American Indians living in Arizona and New Mexico and are not generalizable to American Indians from other regions of the country. Mortality data were from the National Center for Health Statistics and from nine of the twelve Indian Health Service Areas.

Alaska Native data are only from the State of Alaska and include incidence and mortality data only.

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## CHAPTER 4: REGIONAL VARIATIONS IN CANCER DATA AMONG INDIGENOUS PEOPLE

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### CHAPTER OBJECTIVES:

- DETERMINE HOW SOUTHWESTERN REGIONAL AND TRIBAL CANCER DATA DIFFER FROM CANCER DATA FROM OTHER GEOGRAPHIC REGIONS AND TRIBES.
- EXAMINE THE VARIABLE INCIDENCE AND MORTALITY RATES AMONG TRIBES, IHS AREAS, AND GEOGRAPHIC REGIONS FOR THE FOLLOWING CANCER SITES:

◆ LUNG	◆ PROSTATE	◆ PANCREAS
◆ COLON/RECTUM	◆ CERVIX	◆ GALLBLADDER
◆ BREAST	◆ STOMACH	

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### INTRODUCTION

This chapter examines geographic regional data, such as those data which exist for specific tribes and from IHS Areas. The mortality data include nine of the twelve IHS Areas. The remaining three IHS Areas are excluded from this chapter due to the acknowledged problem of underreporting "American Indian" on death certificates. Unfortunately, those three IHS Areas include the two states which, according to the 1990 U.S. Census, have the largest numbers of American Indians: Oklahoma and California.

Regional incidence data are provided for nine IHS Areas and nine tribal groups. The bar graphs in this chapter include tribal and IHS Area data for eight cancer sites. Cancer sites were selected for inclusion in this chapter based on the age-adjusted cancer incidence, mortality and survival data for the sites of most concern among American Indians and Alaska Natives. The cancer sites to be discussed include: lung, colon and rectum, breast, prostate, cervix, stomach, pancreas, and gallbladder. The cancer sites and respective graphs are sequenced in order of highest to lowest cancer incidence rates. The tribes and IHS Areas are alphabetized and separate graphs are provided for males and females.

## **IHS CANCER INCIDENCE DATA FOR GEOGRAPHIC REGIONS AND TRIBES**

The Indian Health Service conducted a study (1993) on cancer incidence among American Indians and Alaska Natives. This study utilized hospital discharge data for 1980-87 to identify cases of cancer for 21 sites in females and 18 sites in males. Cancer sites were selected for inclusion in the analysis if their rate in either sex (directly age-adjusted to the 1970 U.S. population) was greater than 10 per 100,000 person-years, or if published studies suggested a rate which was significantly different than in the non-Indian population. The IHS Inpatient Data System includes a standard data set for each patient discharged from an IHS or contract facility.

### **IHS Areas and Tribes Included in the Study**

Data were examined for nine IHS Areas (Tucson data were analyzed with Phoenix; California and Nashville were excluded) and nine major tribal groups for whom hospital discharge data are available: Apache (includes communities of White River and San Carlos in Arizona and Mescalero, New Mexico), Tohono O'Odham and Pima (communities from Sells and Sacaton, AZ), Navajo (communities on the Navajo reservation in northwestern New Mexico and northeastern Arizona), Sioux (communities from North and South Dakota), Oklahoma Cherokee (living in Oklahoma and identified themselves as Cherokee), Eastern Cherokee (living in North Carolina and identified themselves as Eastern Band Cherokee), and Eskimo (i.e., Inupiaq and Yupik), Athapaskan, Aleut (from appropriate aggregations of the communities in Alaska).

### **Incidence Rates and Confidence Intervals--Appendix E**

Appendix E includes an excerpt from the Indian Health Service incidence study for the eight cancer sites highlighted in this chapter. The Appendix includes the rate and confidence intervals. The IHS calculated 95% confidence intervals for rates. Confidence intervals provide information on the stability of the calculated rates. Narrow confidence intervals indicate that a rate is estimated with more certainty than rate calculations which include broad confidence intervals.

This chapter includes incidence and mortality data which have been age-adjusted (1970 U.S. Standard) per 100,000 population to allow for comparisons. To assist the reader, maps which identify IHS Areas and geographic regions where the specific tribes *for which incidence data are included*, are on the following page.

Figure 4.1 Map of the IHS Administrative Area Offices

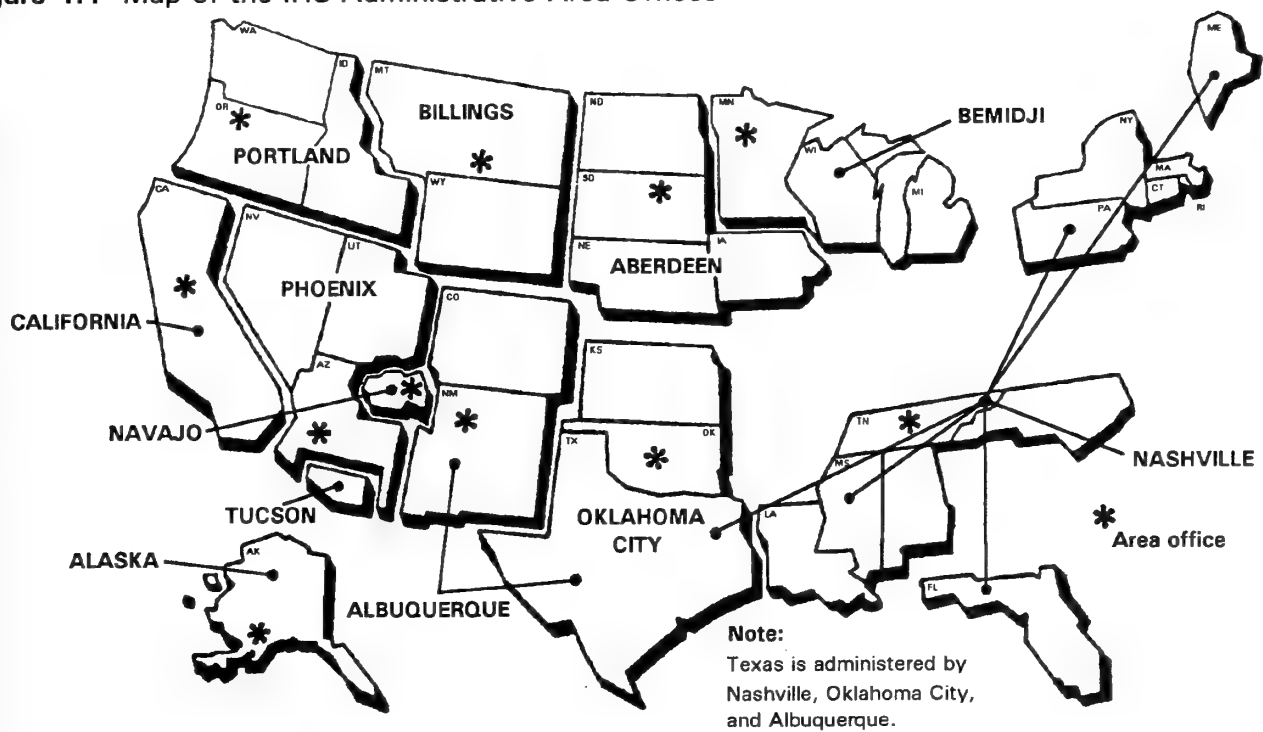
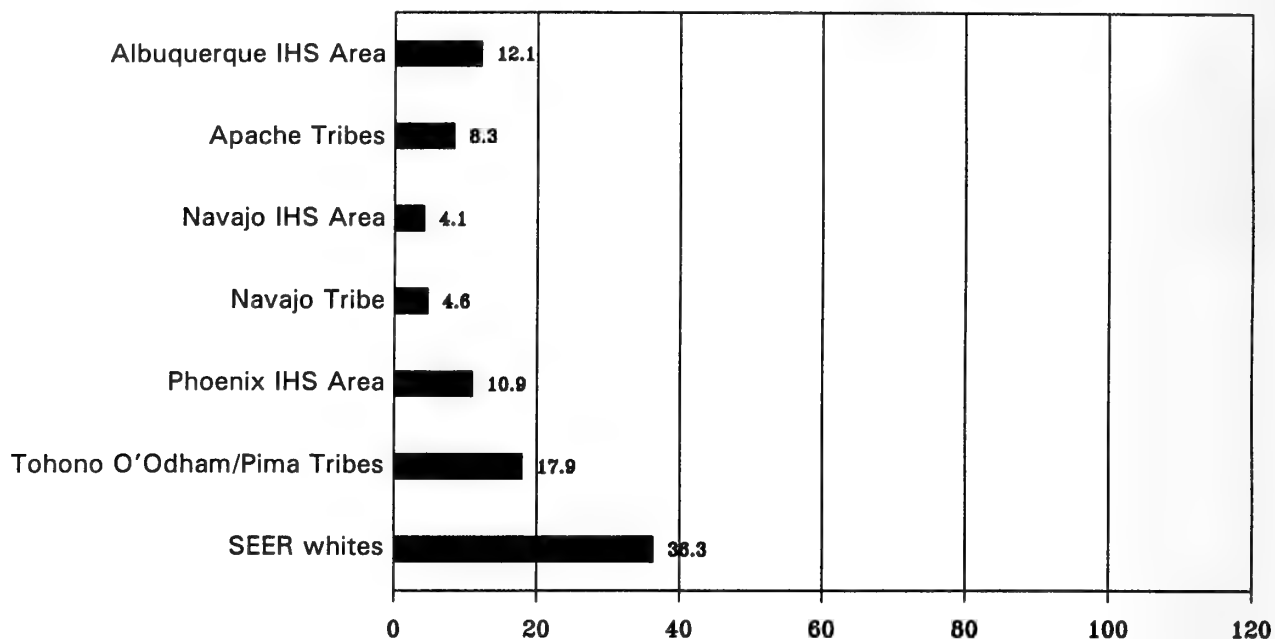


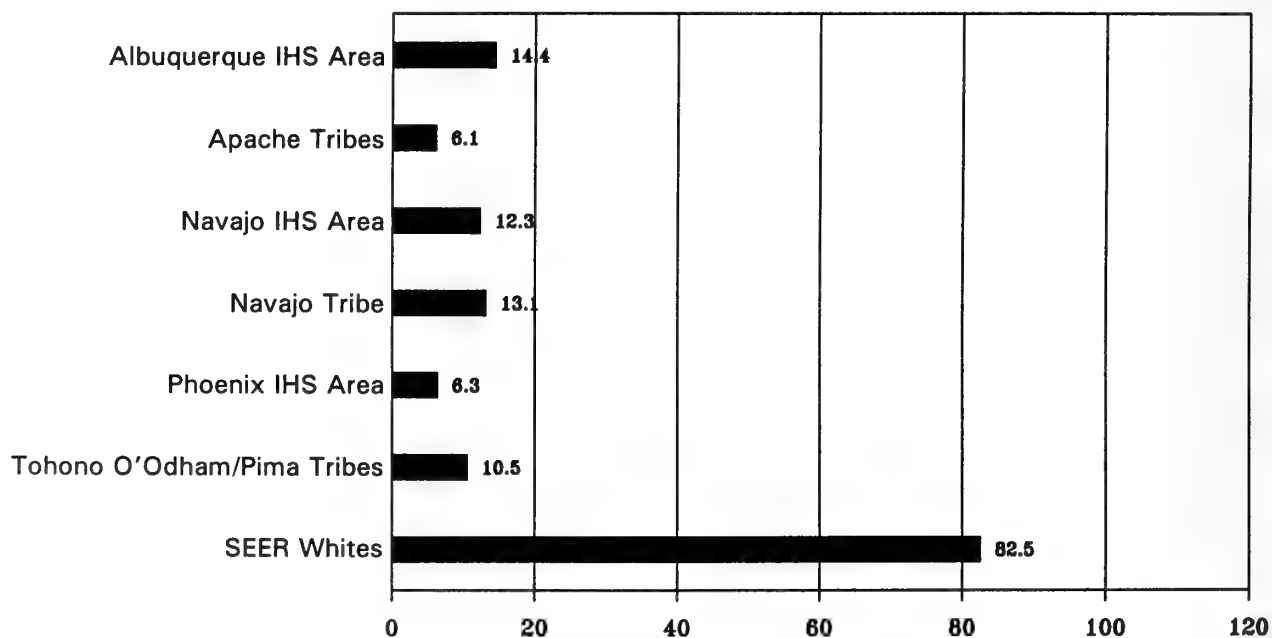
Figure 4.2 Map of Selected Tribes for which Incidence Data are Included in this Chapter.



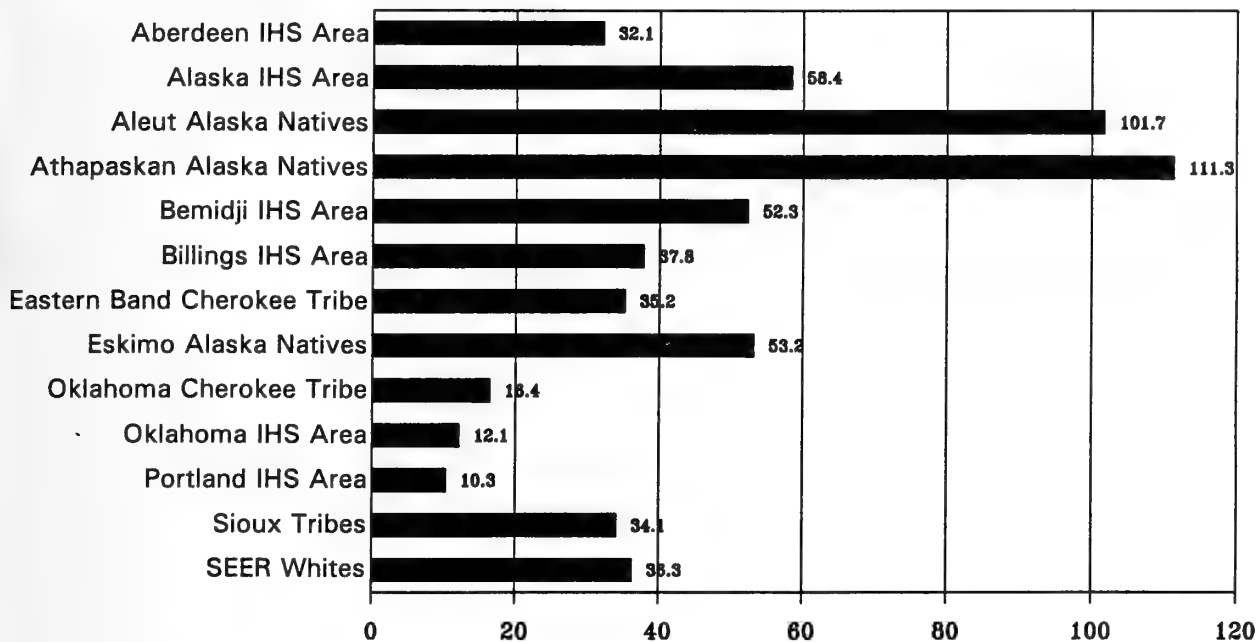
**Graph 4.1** Southwestern American Indian Females: Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, 1982-1987<sup>1</sup>



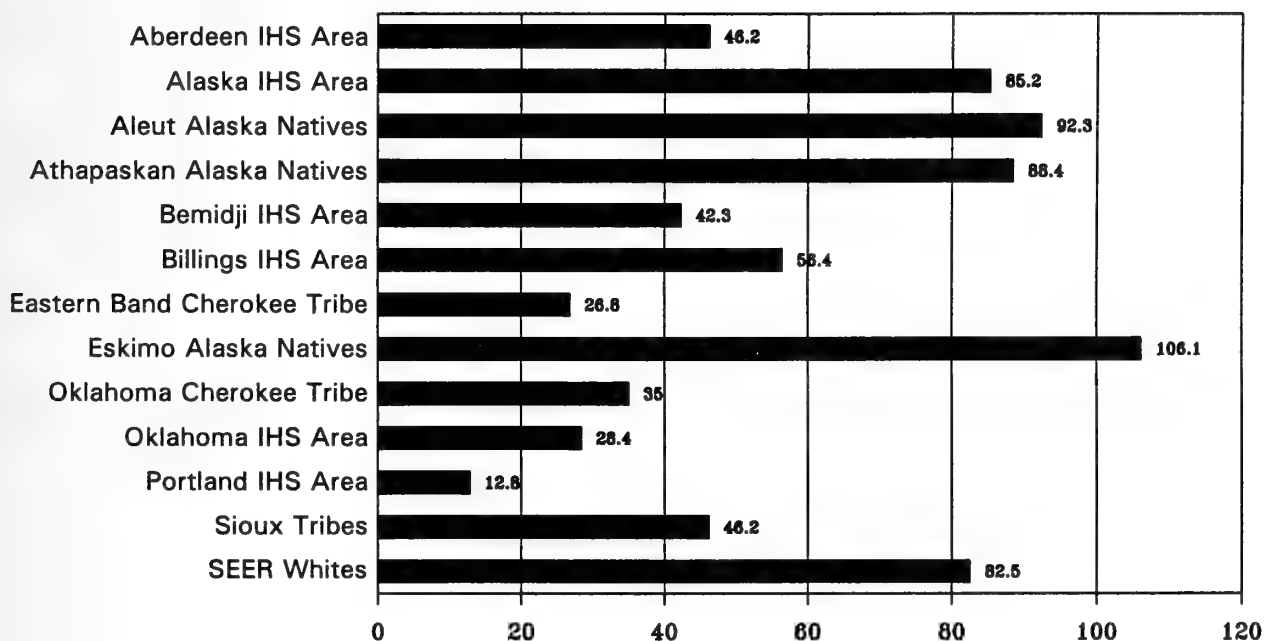
**Graph 4.2** Southwestern American Indian Males: Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, 1982-1987<sup>1</sup>



**Graph 4.3** Non-Southwestern American Indian and Alaska Native Females: Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, 1982-1987<sup>1</sup>



**Graph 4.4** Non-Southwestern American Indian and Alaska Native Males: Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, 1982-1987<sup>1</sup>



## **LUNG CANCER**

### **Lung Cancer Incidence Rates**

According to the New Mexico SEER, lung cancer incidence rates of both sexes of American Indians living in Arizona and New Mexico is 7.3 per 100,000 which is significantly lower than the white rate of 56.2 per 100,000. The lung cancer incidence rates among Alaska Natives are only slightly lower than the white rates. Alaska Natives, both sexes, have a rate of 46.9. Based on this New Mexico and Arizona database, the male American Indian lung cancer incidence rate is 10.5 (white rate is 88.6) and the female American Indian rate is the lowest of any U.S. racial group at 4.4 (white female rate is 33.3). The Alaska Native male rate is 69.7 and the Alaska Native female rate 23.2.<sup>2</sup>

The New Mexico SEER database is the most commonly used data for NCI reports. However, as regional data are examined, it becomes obvious that these data are not representative of American Indians living in other regions of the country and cannot be used to generalize to them. Of the limited non-SEER incidence data available, the IHS areas which overlap the New Mexico SEER database include Phoenix, Albuquerque, Navajo and Tucson. The only tribal data which are available and would also overlap this SEER database are Apache, Tohono O'Odham/Pima, and Navajo. Incidence data for Southwestern tribes are in Graphs 4.1 and 4.2. In comparison, the non-southwestern tribes are shown in Graphs 4.3 and 4.4.

### **Lung Cancer Mortality Rates**

According to the National Center for Health Statistics death records, the age-adjusted lung cancer mortality rates for both sexes for American Indians is 18.1 per 100,000. The rate for Alaska Natives, both sexes, is 40.1 per 100,000, which closely approximates the U.S. All Races rate of 41.5/100,000.

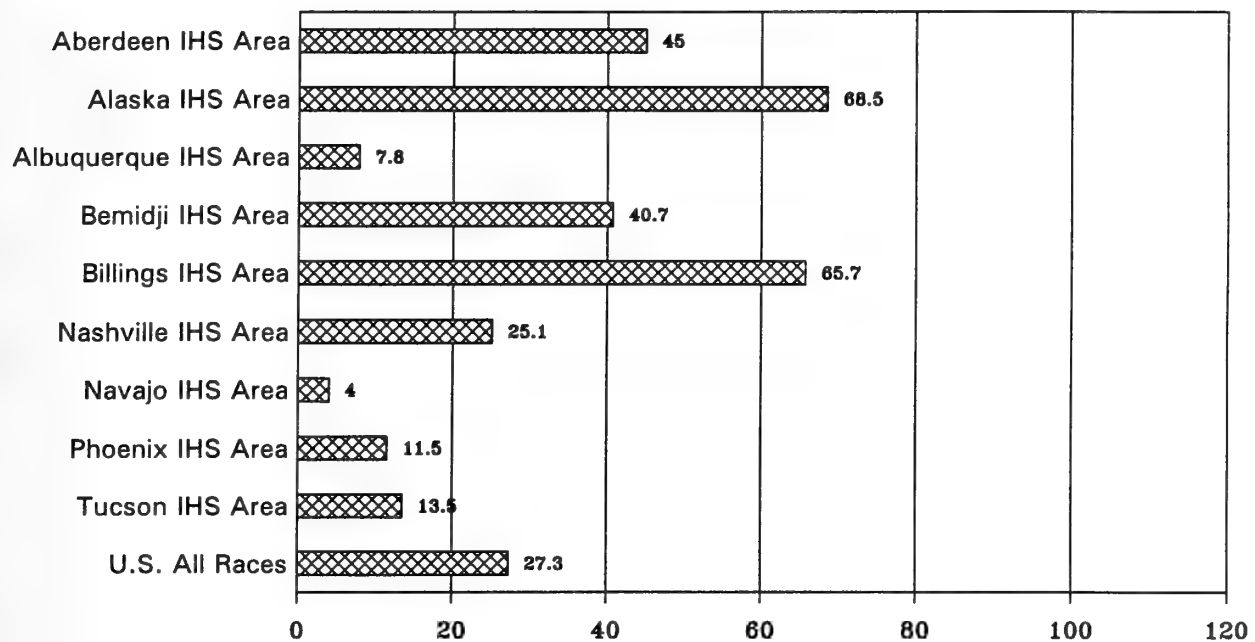
The American Indian lung cancer mortality rate for males is 28.2. The Alaska Native male rate of 64.9 closely approximates the white rate of 69.5. American Indian female lung cancer mortality rates are among the lowest for all ethnic groups with a rate of 9.3. Alaska Native women have a rate of 15.0 and white women for a rate of 20.9.

The racial misclassification and subsequent undercounting of American Indians and Alaska Natives on death certificates becomes obvious when regional data are examined. Nine of the twelve IHS areas are included in Graphs 4.5 and 4.6. California, Oklahoma, and Portland IHS areas are excluded due to underreporting of Indian race on death certificates.<sup>3</sup>

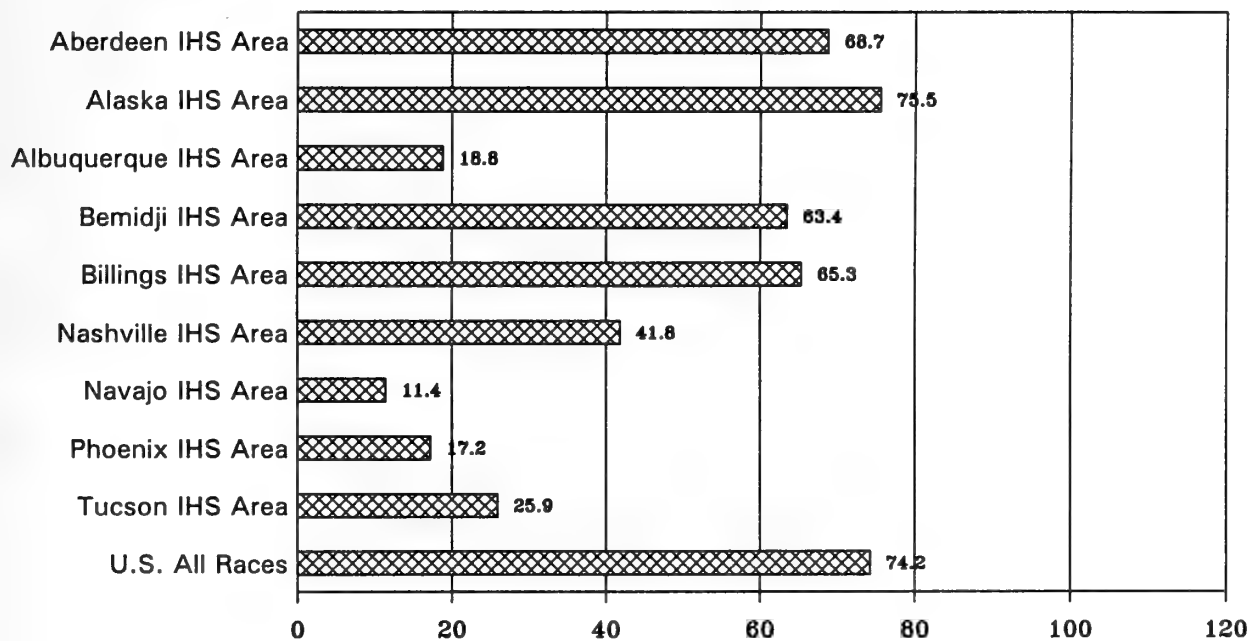
### **Lung Cancer Survival**

The five-year relative survival for lung cancer among American Indians living in Arizona and New Mexico is the poorest of any racial group, 8.9 percent reported in the New Mexico SEER. The white rate is 13.8 percent. American Indian women living in New Mexico and Arizona have poorer survival (14.1 percent) than do white women (17.1 percent) in the same geographic area. Survival data are not available for Alaska Natives.<sup>2</sup>

**Graph 4.5** Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>



**Graph 4.6** Age-Adjusted (1970 U.S. Standard Population) Lung Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>3</sup>



## COLON AND RECTUM CANCER

### Colon and Rectum Cancer Incidence Rates

Alaska Natives living in the state of Alaska have the highest age-adjusted colon and rectum cancer incidence rate per 100,000 population for both sexes (Alaska, 1977-83) in comparison with all other racial groups, such as blacks and whites. The Alaska Natives rate is 62.6/100,000 and the white rate is 52.8/100,000. The American Indian both sexes colon and rectum cancer incidence rate is significantly lower among American Indians living in Arizona and New Mexico, with a rate of 10.2 per 100,000.

When tribal and IHS Area data are reviewed, the most striking data are for Alaska Natives. Alaska Native males have a colon and rectum cancer incidence rate of 61.0 which is similar to the white male rate of 64.5. Aleut males have a colon and rectum cancer incidence rate of 114.8. Other Alaska Native male groups are significantly lower in colon and rectum incidence rates. Eskimo males have a rate of 53.2 and Athapaskan Alaska Native males have a rate of 40.4.

The American Indian male colorectal incidence rate from Arizona and New Mexico is the lowest of any racial group at 10.6.

Alaska Native female colon and rectum incidence rate is the highest of any racial group with a rate of 65.2 (the second highest rate is 45.9 for black women). Aleut females also have a high rate (89.9), but in comparison to the other Alaska Native groups, their rate is the lowest. Eskimo Alaska Native women have the highest rate of any other Alaska Native group at 116.1 and Athapaskan women have a rate of 96.2.

The white female rate in comparison is 44.9 and the American Indian female rate from Arizona and New Mexico is exceptionally low at 10.0.

Among American Indians, the Bemidji Area is the only area which has elevated rates. The Bemidji male rate of 58.0 is very similar to the SEER white rate. The Bemidji female rate of 57.7 is a higher incidence than white women.

### Colon and Rectum Cancer Mortality Rates

Age-adjusted (1970 U.S. Standard) colon and rectum cancer mortality rates per 100,000 (1977-83) for both sexes identify Alaska Natives as having the highest rate at 24.6. American Indians have a very low mortality rate at 9.0. The white, both sexes rate is 21.3. In comparison, white males have the highest age-adjusted mortality rate of any racial group with 25.6. Alaska Native males rate is 22.1 and American Indian males remains low at 10.1. Alaska Native females have the highest mortality rate at 27.2 of any racial group. The white female rate is 18.4 and the American Indian rate is 8.0.<sup>2</sup>

Regional IHS data also indicate that the high Alaska Native female rate of 33.0, which was significantly higher than both the U.S. All Races rate and any of the other eight IHS Area rates. All of the other rates for both American Indian and Alaska Native males and females are lower than U.S. All Races. Five of the IHS Areas had colon and rectum cancer mortality rates



which were significantly lower than the U.S. All Races rate. The Navajo IHS Area was less than 1/4 the U.S. All Races rate. Examination of the male data indicated that six of the nine IHS Areas had rates significantly lower than the U.S. All Races rates and the Tucson Area was less than 1/12 the U.S. All Races rate.<sup>3</sup>

### **Colon and Rectum Cancer Survival**

American Indians, both sexes, have the poorest five-year relative survival (1975-84) for colon and rectum cancer than any other race, such as blacks, white, Hispanic, with a percent of 38.0.<sup>2</sup> The white percent is 53.1. In addition, American Indian males also have the poorest five year survival (33.0 percent) from colon and rectum cancer in comparison with all other races. The white male percent is 52.8. American Indian females also have the poorest survival of any race at 42.3 percent. The white female survival is 53.6. percent.

## **BREAST CANCER**

### **Breast Cancer Incidence Rates**

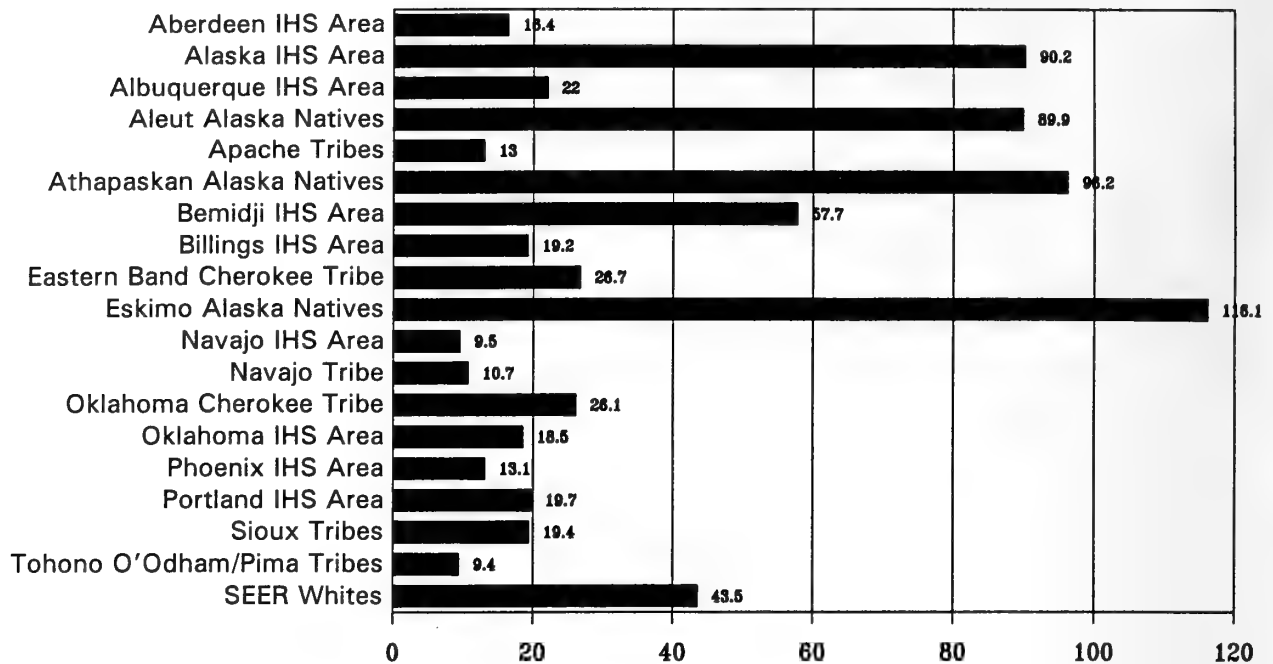
Based upon data from American Indian women living in Arizona and New Mexico, the age-adjusted breast cancer incidence rates are much lower among Indigenous women (rate of 21.7) than among white women (rate of 93.3). Alaska Native women also have lower breast cancer incidence with a rate of 44.2. However, regional variability among breast cancer incidence data is apparent. The age-adjusted incidence of breast cancer is lower among American Indian women of the lower 48 states, as well as among Aleuts and Eskimos. However, Athapaskan Alaska Native women have a rate comparable to the U.S. female rate. American Indian women who live in the northern states have higher rates (e.g., Sioux tribes, Aberdeen IHS, Billings IHS).

### **Breast Cancer Mortality Rates**

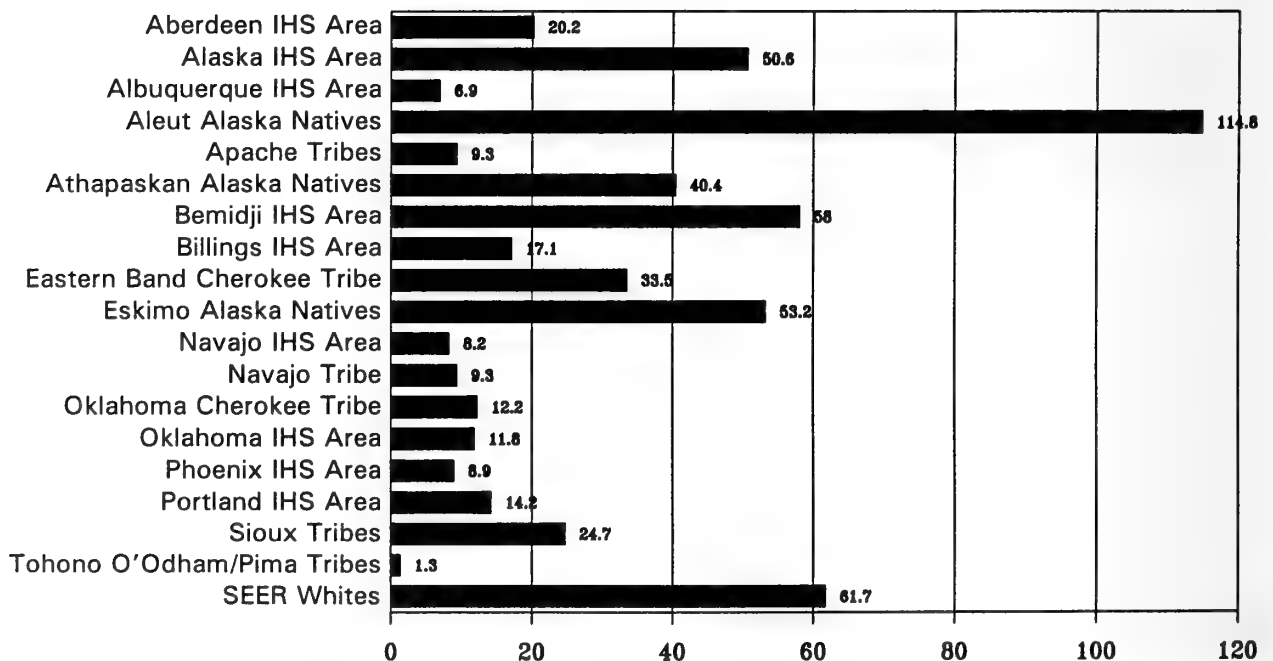
According to national mortality data, the age-adjusted breast cancer mortality rates are also lower for American Indian females (9.0 per 100,000) and Alaska Native females (12.8 per 100,000) than the white rate (26.7 per 100,000). While these data suggest that breast cancer is not a highly prevalent cancer among American Indians and Alaska Natives, errors due to racial misclassification may enter into the discussion. Health providers may erroneously conclude that breast cancer is not a problem. Therefore, it may not be a high priority to have baseline mammograms, referrals for lumps are sometimes prioritized as low as a "seven" on the IHS priority list (which can result in a year delay for referral for abnormal clinical breast examination), and so on. However, when IHS Areas mortality data are examined, once again variations are evident.

The age-adjusted breast cancer mortality rates for nine IHS Areas is 16.1 (California, Oklahoma and Portland IHS Areas omitted due to acknowledged problems in underreporting of Indian race on death certificates). Six of the nine IHS Areas had significantly lower rates than white rates. It is not known why the rate is significantly lower among Indigenous women. Unfortunately, a recent review of the limited trend data indicate that the breast cancer mortality rates are increasing.<sup>4</sup>

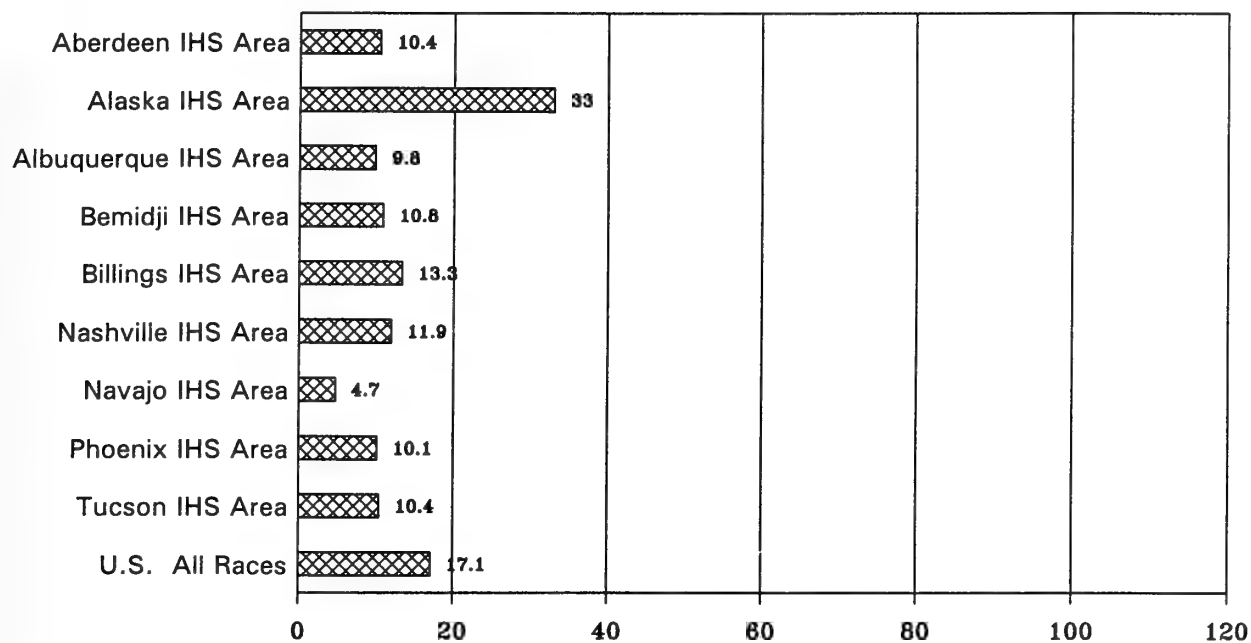
**Graph 4.7** Age-Adjusted (1970 U.S. Standard Population) Colorectal Cancer Incidence Rates per 100,000 Population for Tribes and IHS Areas, Females 1982-1987<sup>1</sup>



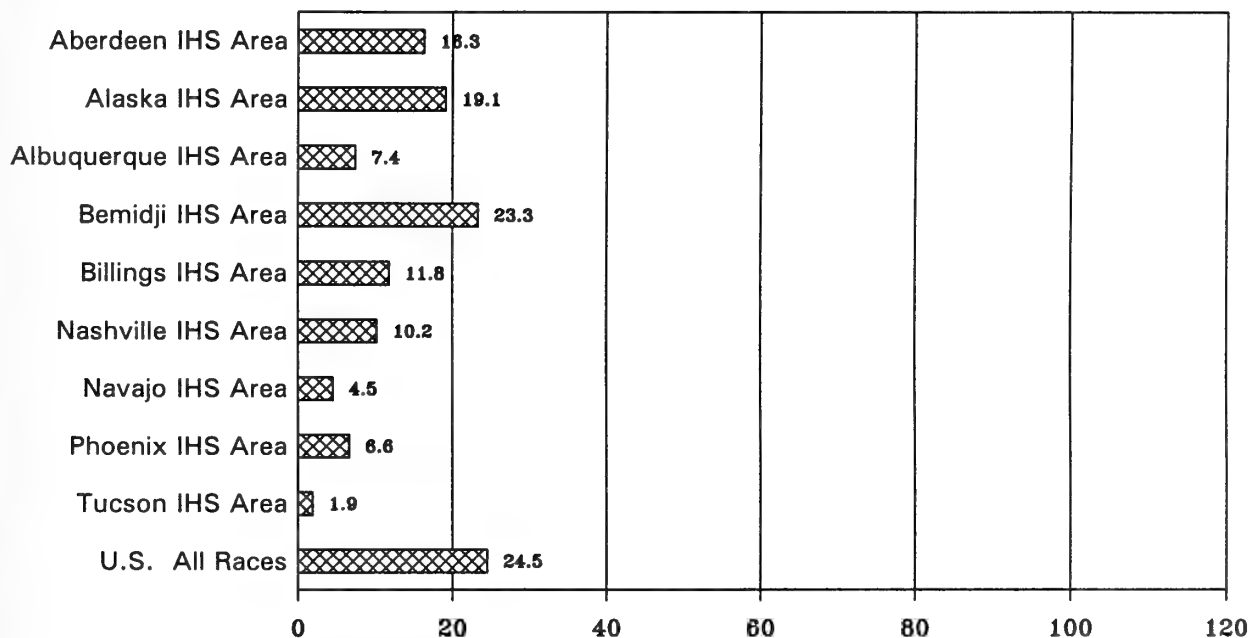
**Graph 4.8** Age-Adjusted (1970 U.S. Standard Population) Colorectal Cancer Incidence Rates per 100,000 Population for Tribes and IHS Areas, Males 1982-1987<sup>1</sup>



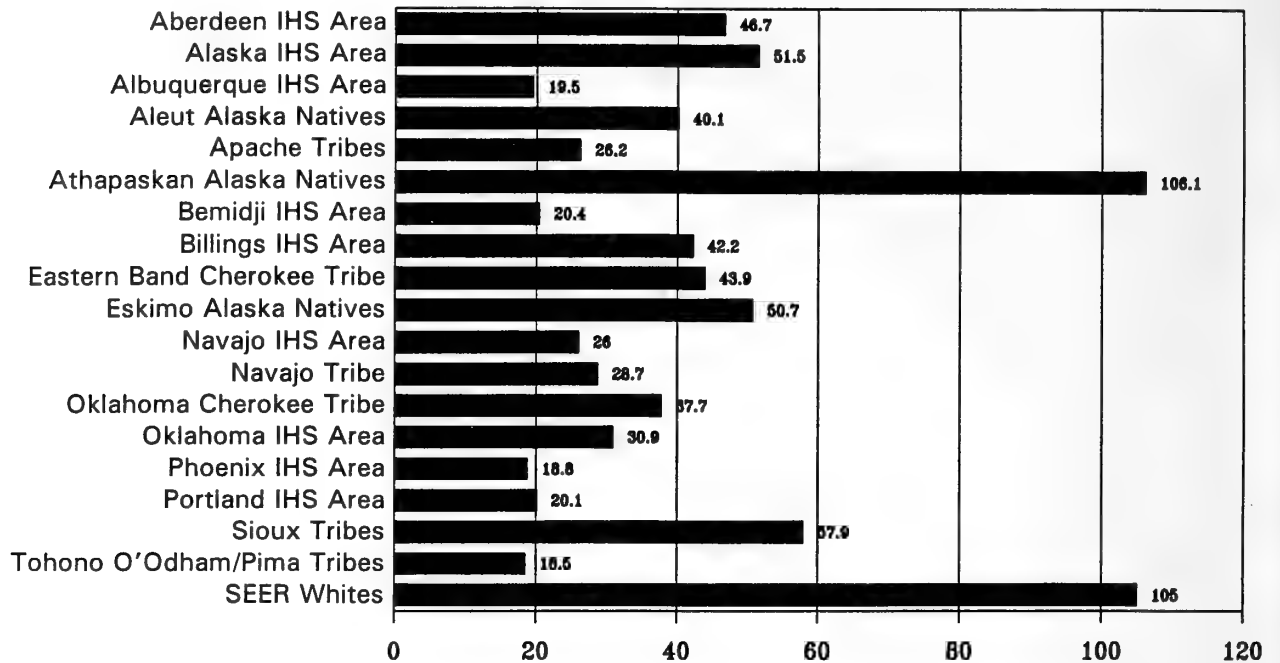
**Graph 4.9** Age-Adjusted (1970 U.S. Standard Population) Colorectal Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>



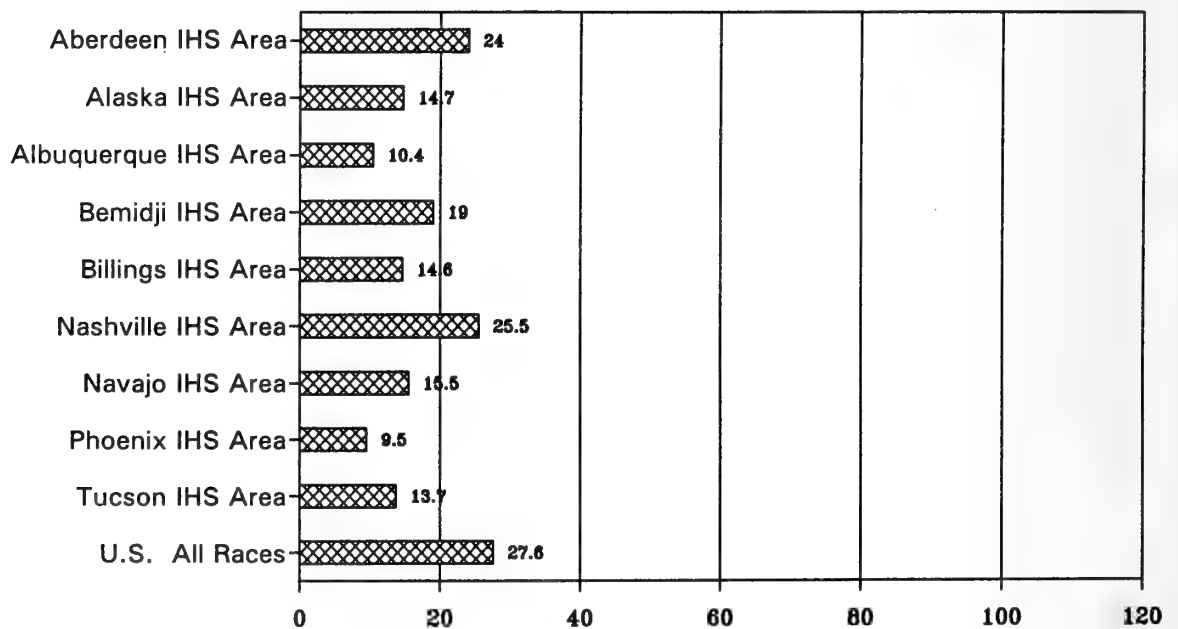
**Graph 4.10** Age-Adjusted (1970 U.S. Standard Population) Colorectal Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>3</sup>



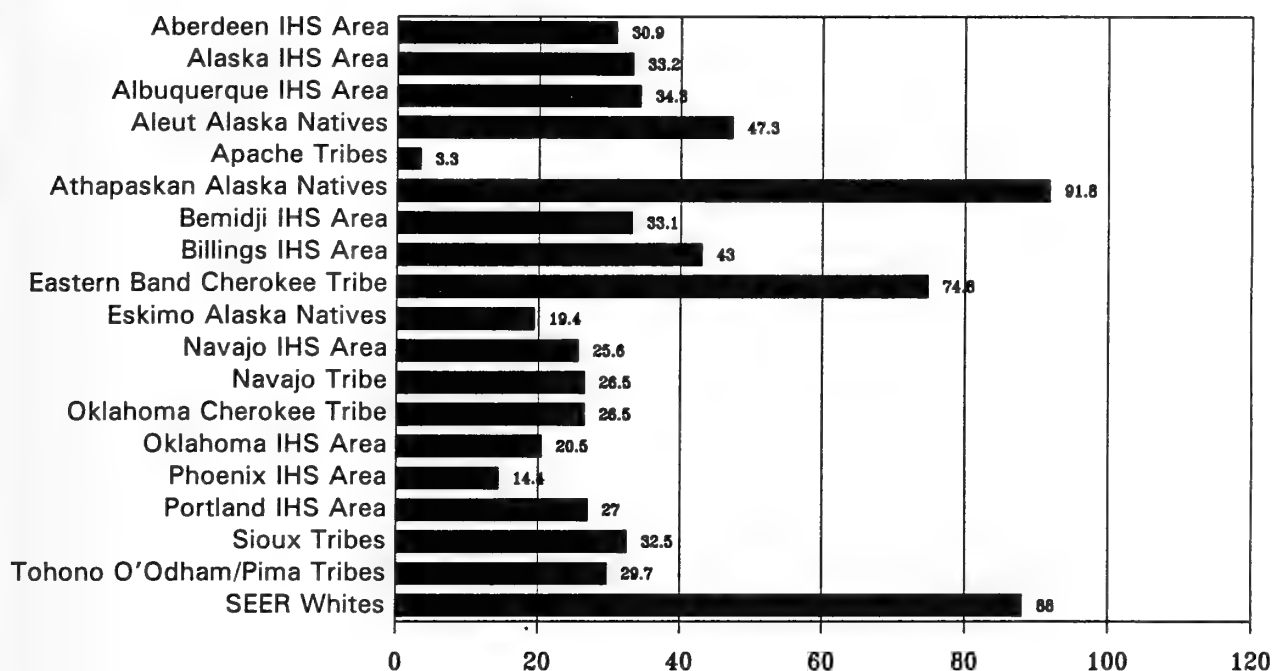
**Graph 4.11** Age-Adjusted (1970 U.S. Standard Population) Breast Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Females 1982-1987<sup>1</sup>



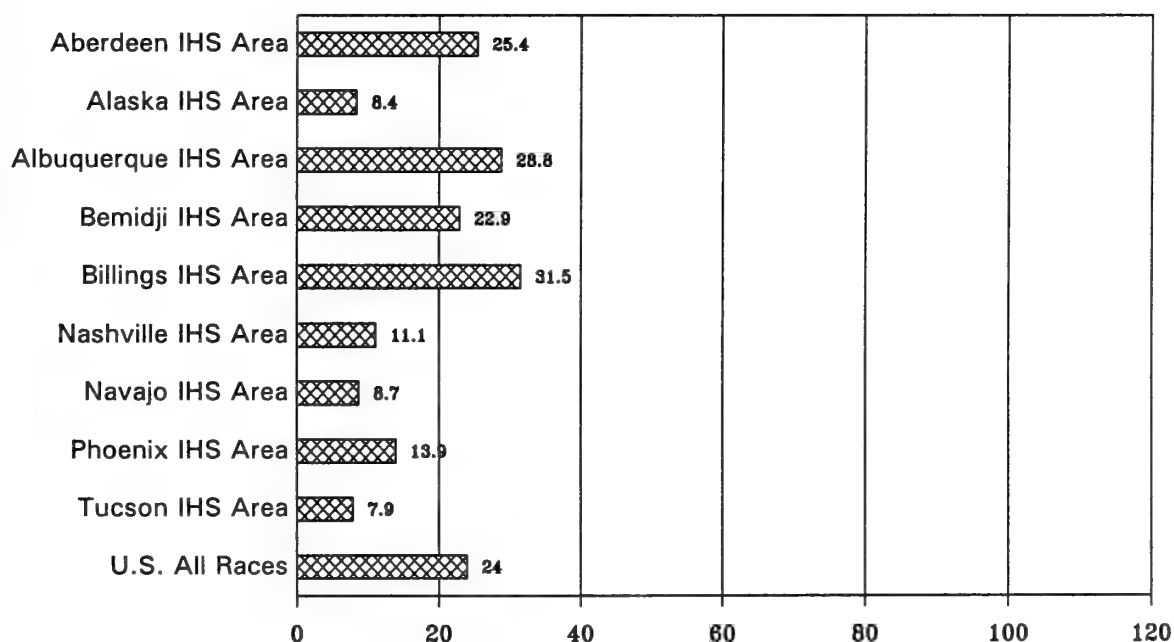
**Graph 4.12** Age-Adjusted (1970 U.S. Standard Population) Breast Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>1</sup>



**Graph 4.13** Age-Adjusted (1970 U.S. Standard Population) Prostate Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Males 1982-1987<sup>1</sup>



**Graph 4.14** Age-Adjusted (1970 U.S. Standard Population) Prostate Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>1</sup>



## **Breast Cancer Survival**

Although the overall breast cancer incidence and mortality rates are lower among American Indian women, according to the New Mexico SEER Registry, American Indian women living in Arizona and New Mexico have the poorest five-year relative survival (46.3 percent) of any racial group. The white female survival percent is 75.7. Alaska Native survival data are not available.

## **PROSTATE CANCER**

### **Prostate Cancer Incidence Rates**

The prostate incidence rates are low among both American Indians living in Arizona and New Mexico (37.6/100,000) and Alaska Natives (34.5/100,000) in comparison with the white rate of 73.6 per 100,000. The regional data among IHS Areas continue to be lower than white rates. The highest rate is 43.0 from Billings, followed by Albuquerque, Alaska and Bemidji. The lowest IHS Area is Phoenix with a rate of 14.4.<sup>1</sup>

Tribal data show a range of incidence rates from 3.3 to 91.8.<sup>1</sup> These variations are not observed in the IHS Area data. Athapaskan Alaska Natives have an elevated prostate cancer incidence rate of 91.8. The Eastern Band Cherokee Tribe has a rate which is significantly higher than other Indian Areas/tribes/bands with a rate of 74.8. The lowest prostate cancer rate is 3.3 for the Apache tribes.

### **Prostate Cancer Mortality Rates**

According the national death records, both American Indians and Alaska Natives have low prostate cancer mortality rates, 11.8 and 11.4 per 100,000 respectively. The highest prostate mortality rate is among black Americans at 44.0 per 100,000. The white rate is 21.1 per 100,000.<sup>2</sup>

The age-adjusted prostate cancer mortality rates for nine IHS Areas is 15.8. However, if the regional data are examined, three IHS Areas have elevated rates: Aberdeen (25.4), Albuquerque (28.8), and Billings (31.5). Five IHS Areas have rates which are significantly lower than the U.S. All races rate. The Tucson Area has the lowest rate of 7.9, which is about 1/3 the U.S. rate.<sup>3</sup> Specific rates for IHS Areas follow:

### **Prostate Cancer Survival**

According to the New Mexico SEER, although the prostate cancer incidence and mortality rates are low among American Indians living in Arizona and New Mexico, in comparison with other racial groups, their survival is poorer. American Indians from Arizona and New Mexico have the poorest five-year relative survival of any race, 51.4 percent. In comparison, the white rate is 69.8 percent. No survival data are available for Alaska Natives.<sup>2</sup>

## **CERVICAL CANCER**

### **Cervical Cancer Incidence Rates**

According to the New Mexico SEER, American Indian women living in New Mexico and Arizona have a cervical cancer (invasive cancer, not in situ) incidence rate of 20.5 per 100,000. Alaska Native women have the highest rate at 28.0. The white female rate is 8.6. When existing incidence data are reviewed, each American Indian and Alaska Native tribe or IHS Area shows a higher incidence than SEER whites.

### **Cervical Cancer Mortality Rates**

According to the Alaska Tumor Registry (1977 to 1983), Alaska Native women have the highest death rate from cervical cancer of any race with a rate of 12.5. According to the National Center for Health Statistics 1977-1983, American Indian cervical cancer mortality rate was 5.5 and the white rate was 3.2. When IHS regional data are reviewed, all IHS Areas have cervical cancer mortality rates higher than the U.S. rate and six of the nine Areas have rates significantly higher than the U.S. rate: Billings, Aberdeen, Nashville, Albuquerque, Alaska, and Navajo.<sup>2</sup>

### **Cervical Cancer Survival**

According to the New Mexico SEER, American Indian women have the second poorest five-year relative survival from cervical cancer rate than all other racial groups with a percent of 65.1. Blacks have the poorest survival of 61.3 percent. The white percent is 67.2. Survival data for Alaska Native women are not available.

## **STOMACH CANCER**

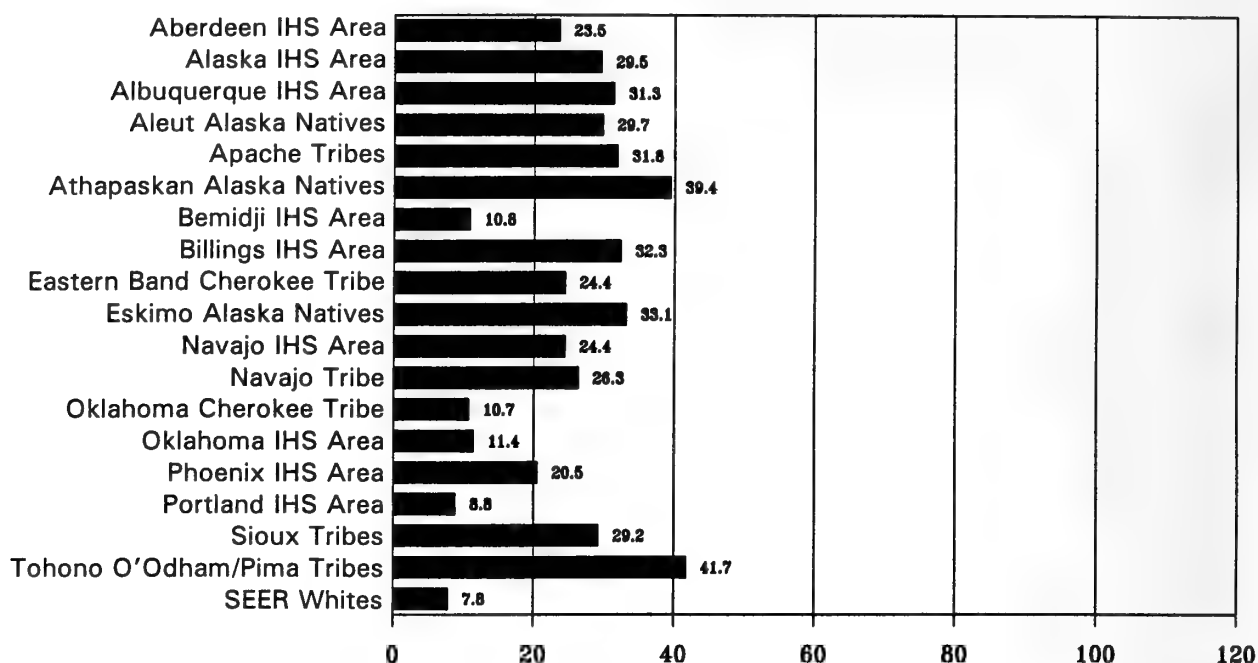
### **Stomach Cancer Incidence**

According to New Mexico SEER Registry 1977-83 age-adjusted rates (1970 U.S. Standard), stomach cancer incidence is high among Indigenous Peoples when compared with whites and is higher among males than females. American Indians living in Arizona and New Mexico have an age-adjusted stomach cancer incidence of 17.6 per 100,000. Alaska Natives living in Alaska have an incidence rate of 15.5 per 100,000. The white rate is 8.9 per 100,000.

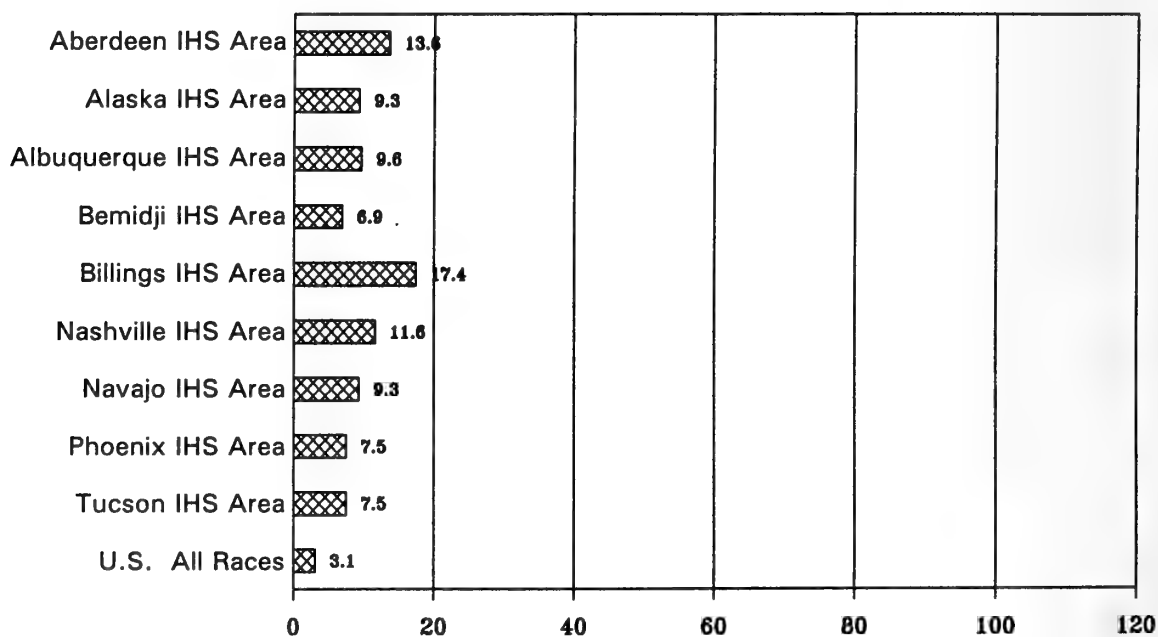
Stomach cancer incidence is higher among males than females, but this difference is particularly pronounced among Indigenous Peoples. Alaska Natives male incidence rate is 22.4, but the Alaska Native female rate is 8.4. American Indian male stomach cancer incidence rate is 22.3 and the American Indian female rate is 13.8. The white male rate is 13.3 compared with the white female rate of 5.8.<sup>2</sup>

As with each cancer site, there is significant variability among IHS Areas and geographically diverse tribes (see Graph 4.17 and 4.18).

**Graph 4.15** Age-Adjusted (1970 U.S. Standard Population) Cervical Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Females 1982-1987<sup>1</sup>



**Graph 4.16** Age-Adjusted (1970 U.S. Standard Population) Cervical Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>





Aleut males have the highest stomach cancer incidence rate (37.4/100,000) and Eskimo males have the second highest incidence rate (28.9). Athapaskan Alaska Natives rate is also high (15.3) but is the lowest in comparison to the other Alaska Native males.

Stomach cancer appears to be higher among American Indians living in New Mexico and Arizona than among other geographic regions, with the exception of the Sioux tribes which are primarily in the Dakotas.

### **Stomach Cancer Mortality**

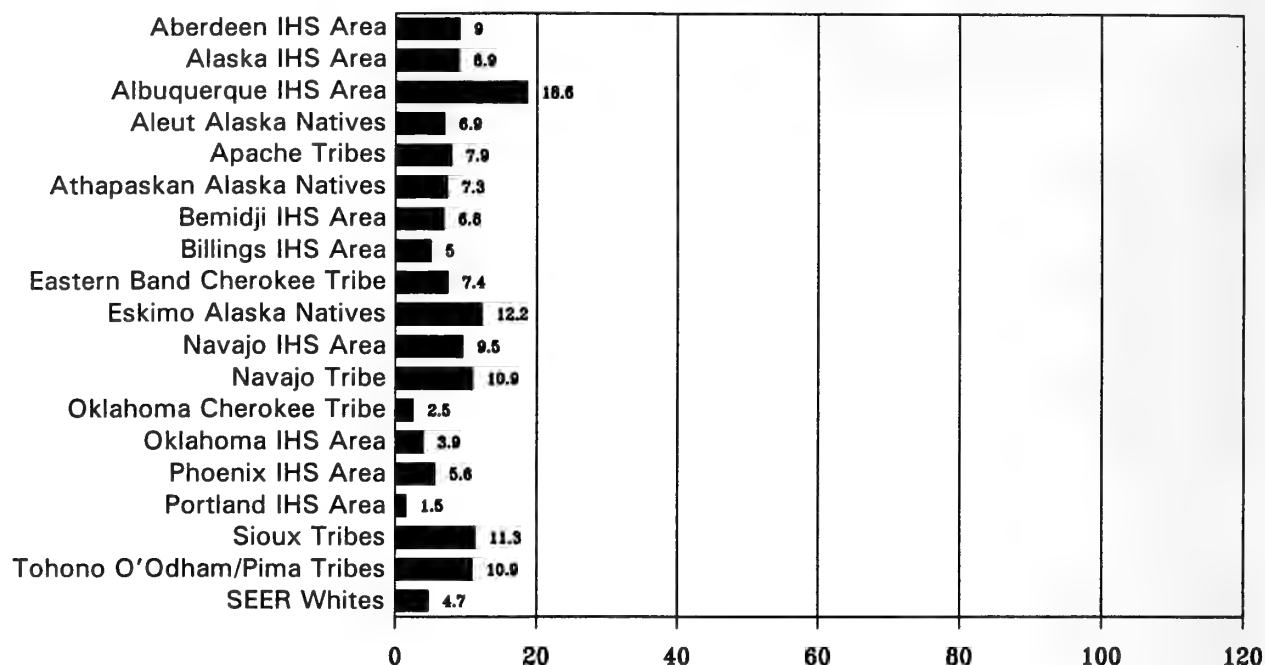
The age-adjusted cancer mortality rates per 100,000 population for both sexes (1977-83) are higher among Alaska Natives with a rate of 11.9 than the white rate of 5.2. The American Indian rate is 5.8. Both American Indian and white males mortality rates are the same at 7.6 per 100,000. However, the Alaska Native male rate is 17.2. In comparison, the female mortality rates for Alaska Natives is 7.0, the American Indian rate is 4.3, and the white rate is 3.6. The stomach cancer mortality rates vary among IHS Areas as Graph 4.19 and 4.20 illustrate.

When data on both sexes are reviewed, Alaska, Billings, Albuquerque, Navajo, and Tucson Areas had stomach cancer mortality rates that were significantly higher than the U.S. All Races rate. As geographic regions are examined, the IHS Areas which are located in Arizona and New Mexico have higher rates among American Indian males, and three IHS Areas, Tucson, Navajo, and Albuquerque, had stomach mortality rates for males that were significantly higher than the U.S. all races rate. The Tucson Area male mortality rate was 2.8 times the U.S. All Races male rate. For females, six IHS areas were significantly higher than the U.S. All Races female stomach cancer mortality rate. Navajo had the highest rate, 3.5 times the U.S. All Races rate.<sup>3</sup>

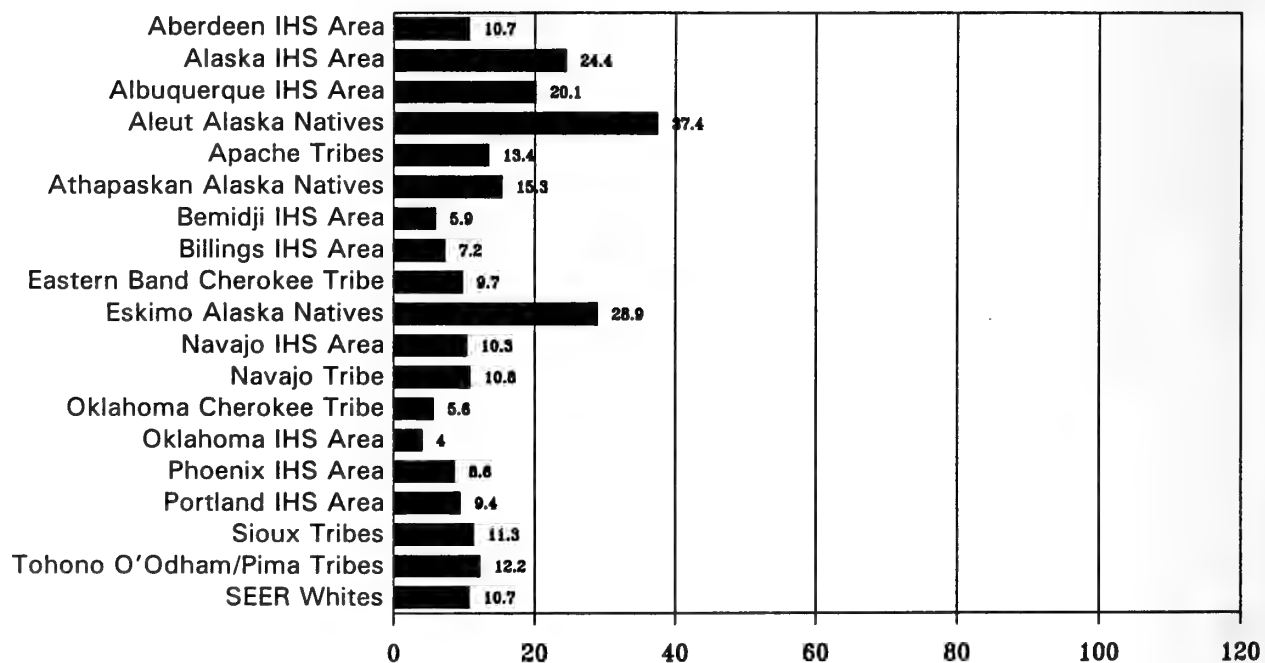
### **Stomach Cancer Survival**

The five-year relative stomach cancer survival figures (percentage) for both sexes (1975-84) identifies American Indians as having the poorest survival at 7.9 when compared with other racial groups, such as blacks, Native Hawaiian, Japanese and whites. The white both sexes percent is 16.5. American Indian males also have the poorest survival from stomach cancer when compared with other racial groups with a percent of 4.7. The white survival is 15.1 percent. American Indian females survival is 12.0 percent, which is the second poorest survival of any race (Filipino have the poorest survival at 8.4 percent). The white female survival is 18.7 percent.<sup>2</sup>

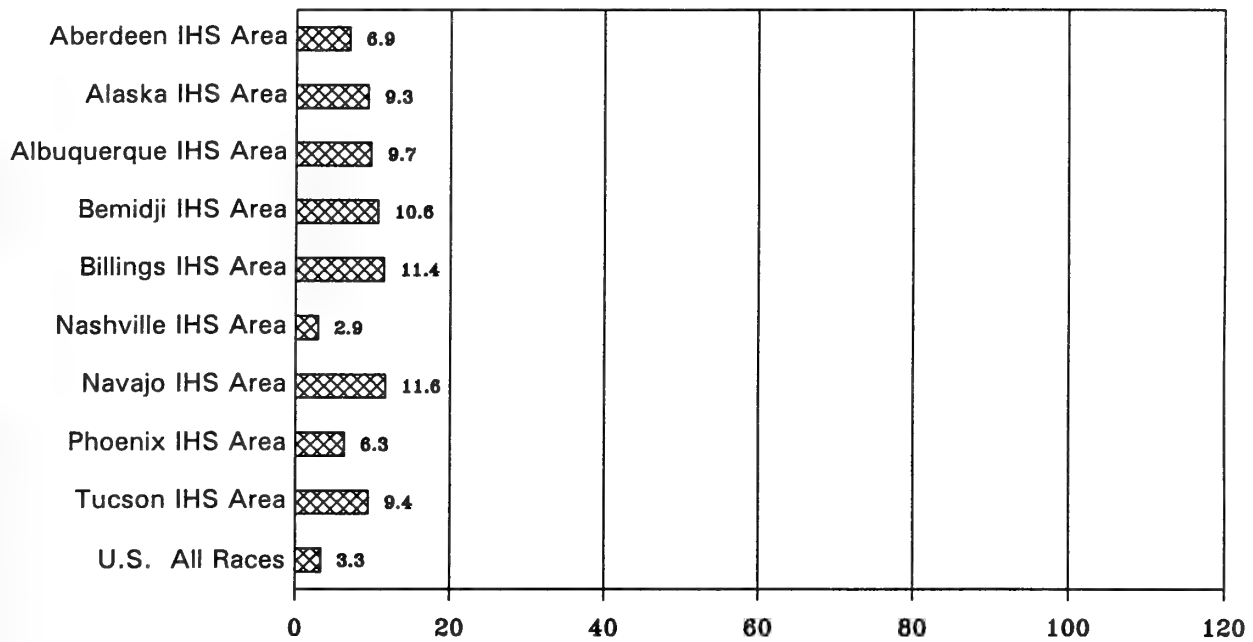
**Graph 4.17** Age-Adjusted (1970 U.S. Standard Population) Stomach Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Females 1982-1987<sup>1</sup>



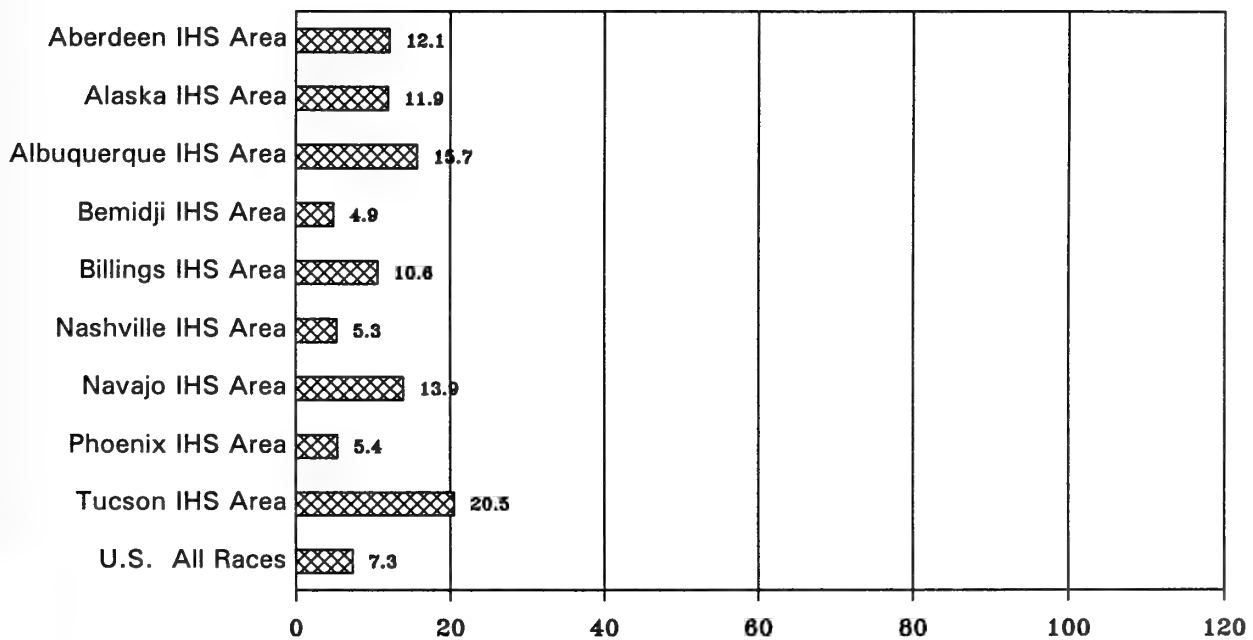
**Graph 4.18** Age-Adjusted (1970 U.S. Standard Population) Stomach Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Males 1982-1987<sup>1</sup>



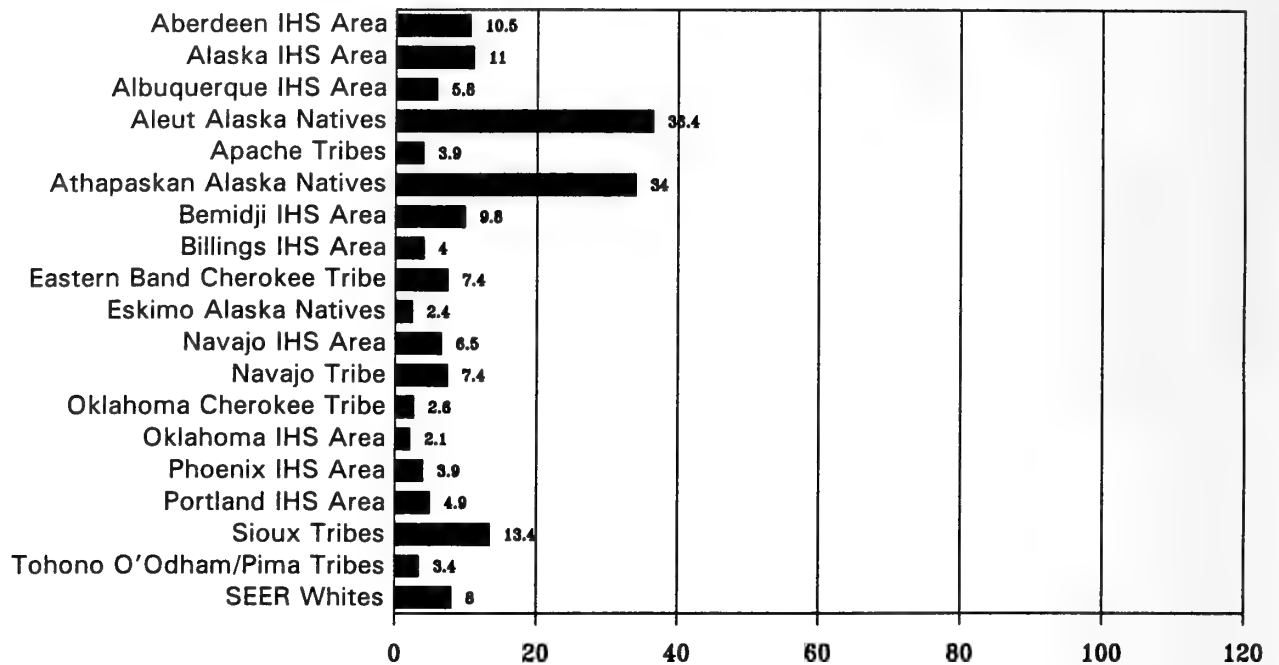
**Graph 4.19** Age-Adjusted (1970 U.S. Standard Population) Stomach Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>



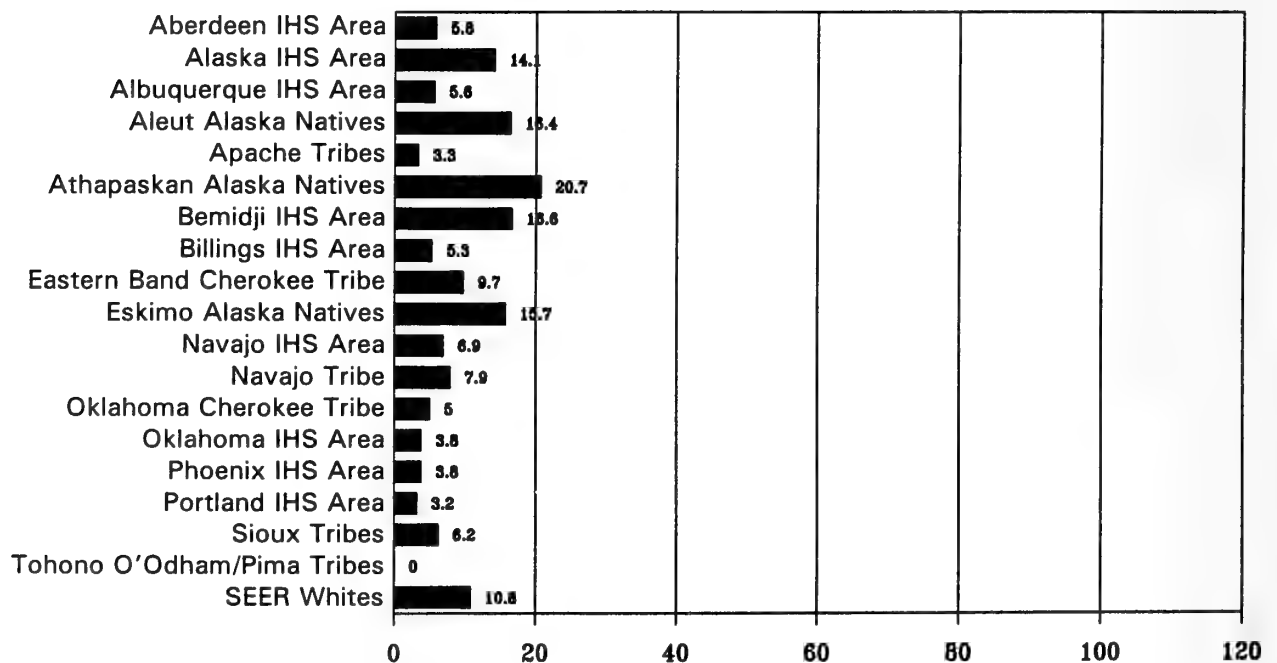
**Graph 4.20** Age-Adjusted (1970 U.S. Standard Population) Stomach Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>3</sup>



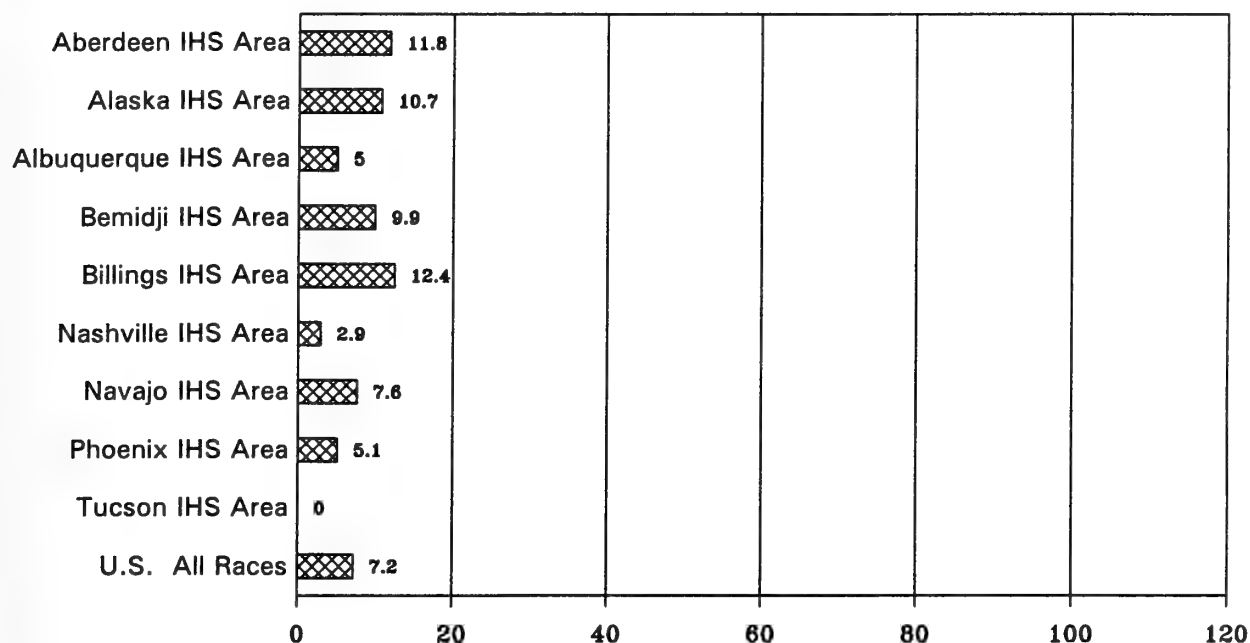
**Graph 4.21** Age-Adjusted (1970 U.S. Standard Population) Pancreatic Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Females 1982-1987<sup>1</sup>



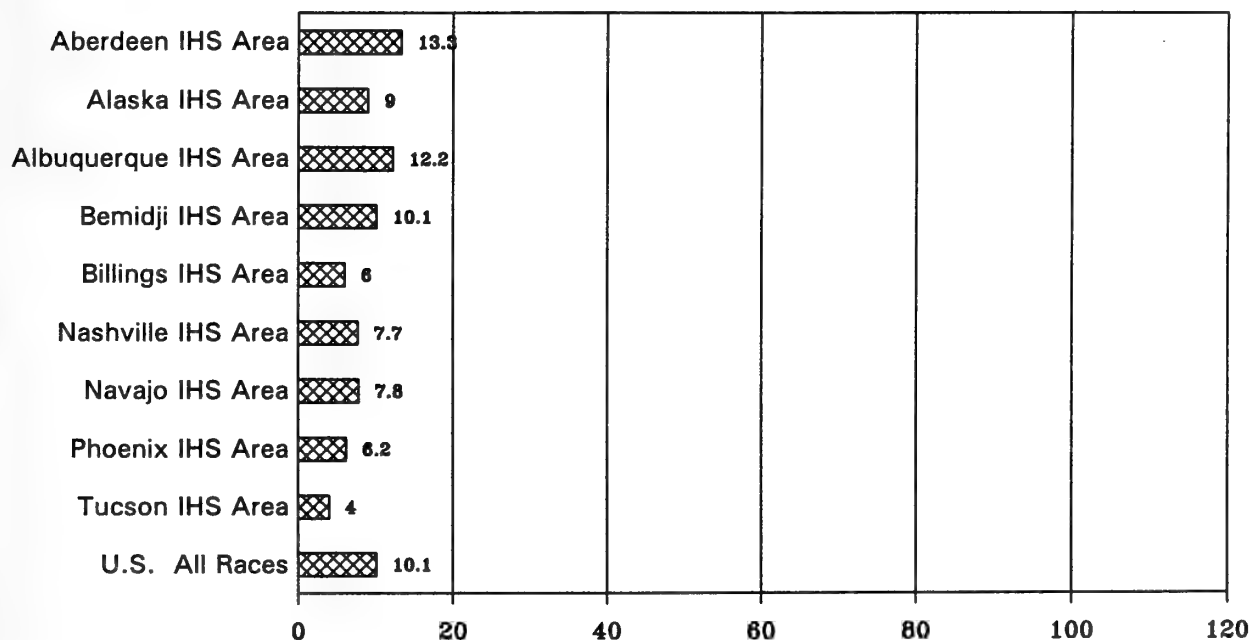
**Graph 4.22** Age-Adjusted (1970 U.S. Standard Population) Pancreatic Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Males 1982-1987<sup>1</sup>



**Graph 4.23** Age-Adjusted (1970 U.S. Standard Population) Pancreatic Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>



**Graph 4.24** Age-Adjusted (1970 U.S. Standard Population) Pancreatic Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>3</sup>



## **PANCREATIC CANCER**

### **Pancreatic Cancer Incidence Rates**

The age-adjusted (1970 U.S. Standard) pancreatic cancer incidence rates per 100,000 population for both sexes indicate that Alaska Natives have higher incidence, but the rate is similar to whites, whereas, the American Indian both sexes rate is the lowest of any race. The pancreatic cancer incidence rate is 9.9 for Alaska Natives, 5.8 for American Indians and 9.5 for whites. The male rates are 10.1 for Alaska Natives and 11.6 for whites. American Indian males have the lowest rate at 7.1. Female rates are 9.6 for Alaska Natives and 7.9 for whites. American Indian females have the second lowest pancreatic cancer incidence rate, 4.5, of any racial group.<sup>2</sup>

A very different picture evolves as regional tribal and IHS Area data are examined. Among Alaska Native males, Athapaskans have a pancreatic cancer incidence rate of 20.7 per 100,000, Aleuts have 16.4 and Eskimos have 15.7. All of these rates are significantly higher than the white male rate. However, the Alaska Native female rates are the most diverse. Aleut women have a rate of 36.4 and Athapaskan women have a rate of 34.0, but Eskimo women have a rate of 2.4.

Among American Indians, males living in the Bemidji IHS Area have a significantly higher incidence rate of 16.6/100,000. Tohono O'Odham and Pima tribes have no reported cases of pancreatic cancer. Sioux women have significantly high pancreatic cancer incidence rates at 13.4. The Aberdeen IHS Area which includes several Sioux tribes and Bands has a rate of 10.5. Females living in the Bemidji IHS Areas also have elevated rates at 9.8.

### **Pancreatic Cancer Mortality Rates**

Age-adjusted (1970 U.S. Standard) pancreatic cancer mortality rates per 100,000 for both sexes (1977-83) were 9.7 for Alaska Natives, 8.3 for whites, and 4.6 for American Indians (the second lowest rate in comparison to other races such as black, Hispanic). Pancreatic mortality rates among males are 9.3 for Alaska Natives, 10.4 for whites and 5.3 for American Indian males, the second lowest rate of any race. Alaska Native women have the highest pancreatic cancer mortality rate, 10.3, of any race. The white female rate in comparison is 6.8 and the American Indian female rate is 4.2.

As IHS Area data are examined, the American Indian female rate is the most diverse, ranging from 12.4/100,000 for the Billings IHS Area to 2.9 for Nashville. Tucson had no deaths due to pancreatic cancer among females. Although the rates were higher among Indian women living in the northern states (Billings, Aberdeen, Bemidji IHS Areas), none were significantly higher than the U.S. All Races female rate.

### **Pancreatic Cancer Survival**

Survival from pancreatic cancer is generally dismal regardless of the racial group. American Indians five-year relative survival from pancreatic cancer, both sexes, 1975-84 is zero. The white survival is 2.9 percent. The American Indian male and female survival is zero.

The white male survival is 3.0 percent and the white female survival from pancreatic cancer is 2.7 percent. The highest survival for women of any race is among Filipino women at 7.2 percent.

## **GALLBLADDER CANCER**

### **Gallbladder Incidence Rates**

Gallbladder cancer incidence rates are disproportionately high among both Indigenous males and females. The incidence rates for whites, both sexes, is 1.3/100,000 compared with incidence of 10.9 for American Indians living in Arizona and New Mexico and 10.6 for Alaska Natives.<sup>2</sup> Gallbladder cancer is 8.4 times more likely to occur in an Indigenous person than in a white person.

The incidence rates for gallbladder cancer are higher among women than men. The American Indian male rate is 6.4, while Alaska Native males have a rate of 6.7, which is the highest of any racial group. The white male gallbladder cancer incidence is 0.9. In comparison, according to New Mexico SEER, American Indian women living in Arizona and New Mexico have an incidence rate of 14.7. Alaska Native females also have an incidence rate of 14.7. These rates are the highest of any other racial group and indicate that gallbladder cancer is approximately nine times more likely to occur in an American Indian or Alaska Native woman than in a white woman. The white female gallbladder incidence rate is 1.6.<sup>2</sup> The gallbladder incidence rates vary among Indigenous men and women from different tribes as well as among different regions. Incidence rates from selected tribes and IHS Areas are included in Graph 4.25 and 4.26.

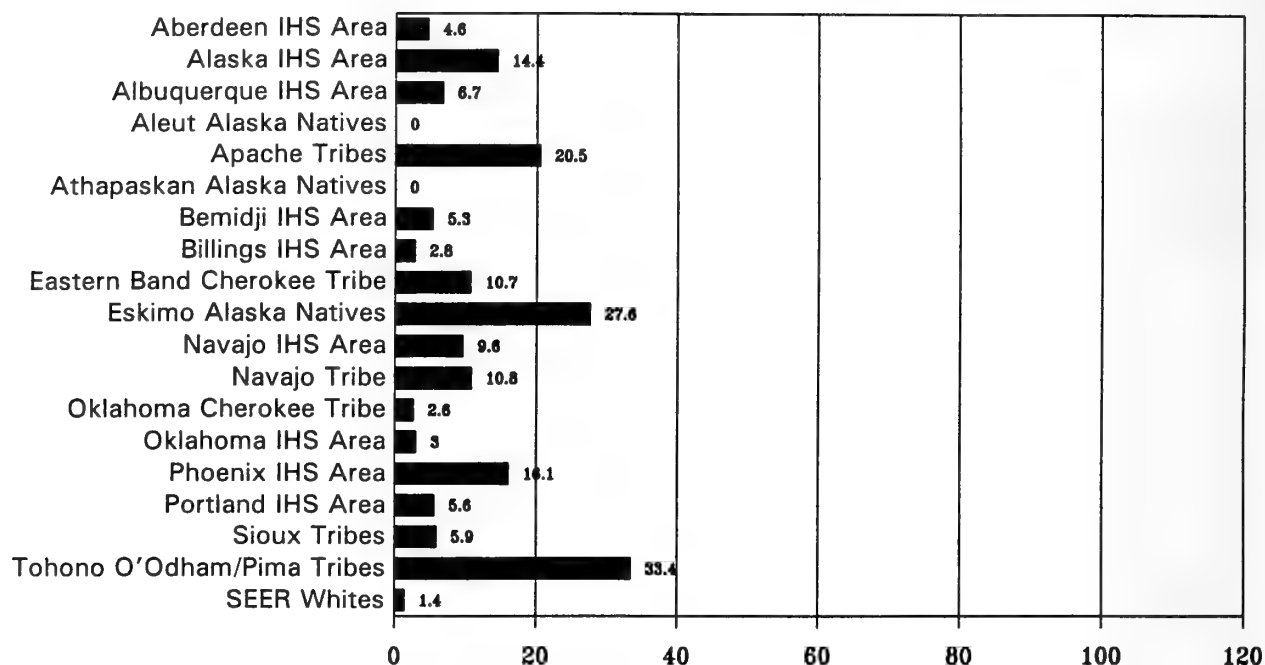
### **Gallbladder Mortality Rates**

American Indians also have disproportionately high gallbladder cancer mortality rates. The age-adjusted mortality rates for American Indians, both sexes, is 2.6/100,000. The Alaska Native rate, both sexes, is the highest of any racial group with a rate of 3.8.<sup>2</sup> Gallbladder mortality rates for both sexes in nine of the twelve IHS Areas is 5.1. The three IHS Areas which are not included in this rate, California, Oklahoma, and Portland) have been omitted due to acknowledged problems of underreporting of Native American on death certificates. In comparison, the white mortality rate for both sexes is 1.0.<sup>1</sup>

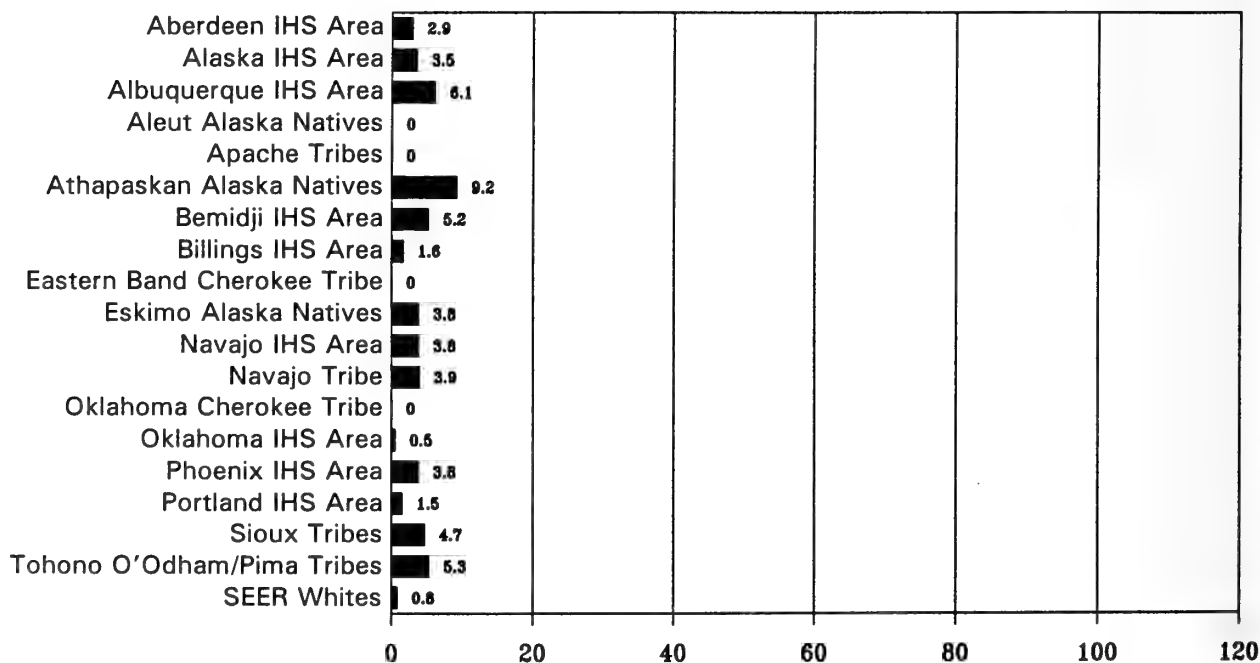
Female death rates from gallbladder cancer are higher than rates for males. American Indian women have a rate of 3.6 and Alaska Native females have the highest rate of any racial group with a rate of 6.3.<sup>2</sup> The female gallbladder mortality rate for nine of the IHS Areas is 7.6. White females have a gallbladder mortality rate of 1.2.

According to National Center for Health Statistics death records, American Indian males have a gallbladder mortality rate of 1.5 which is the highest of any racial group. Alaska Native males are also exceptionally high with a rate of 1.4. In comparison, the white male rate is 0.6.<sup>2</sup> The IHS average mortality rate for nine areas is 2.3.<sup>3</sup>

**Graph 4.25** Age-Adjusted (1970 U.S. Standard Population) Gallbladder Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Females 1982-1987<sup>1</sup>

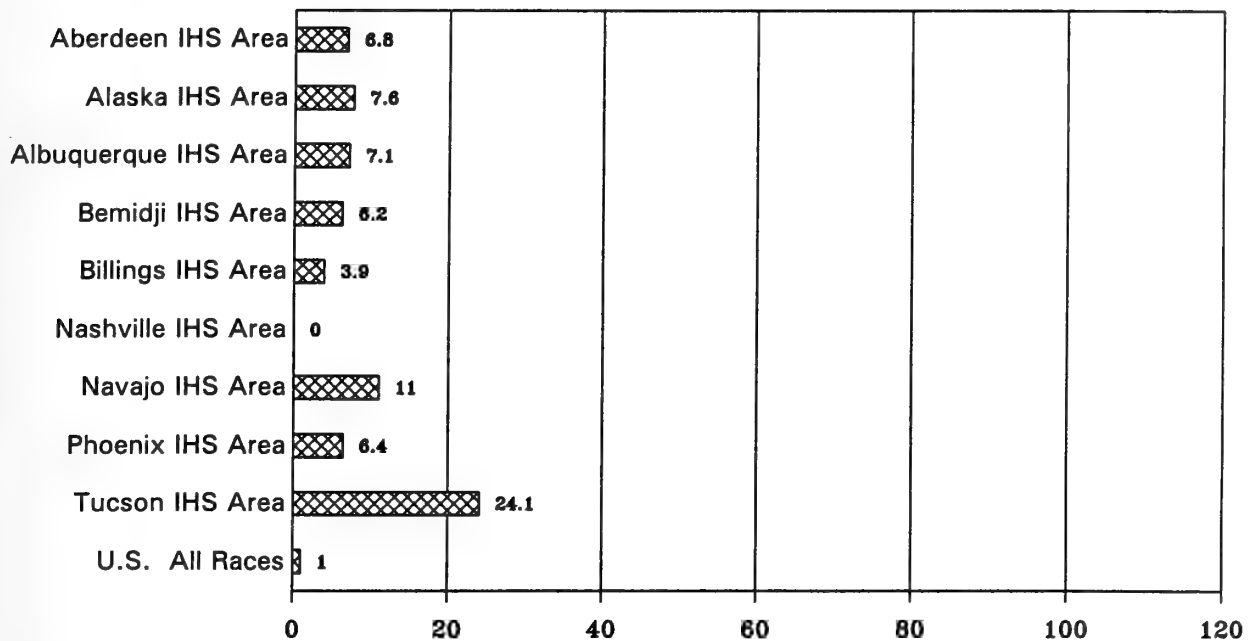


**Graph 4.26** Age-Adjusted (1970 U.S. Standard Population) Gallbladder Cancer Incidence Rates per 100,000 Population for selected Tribes and IHS Areas, Males 1982-1987<sup>1</sup>

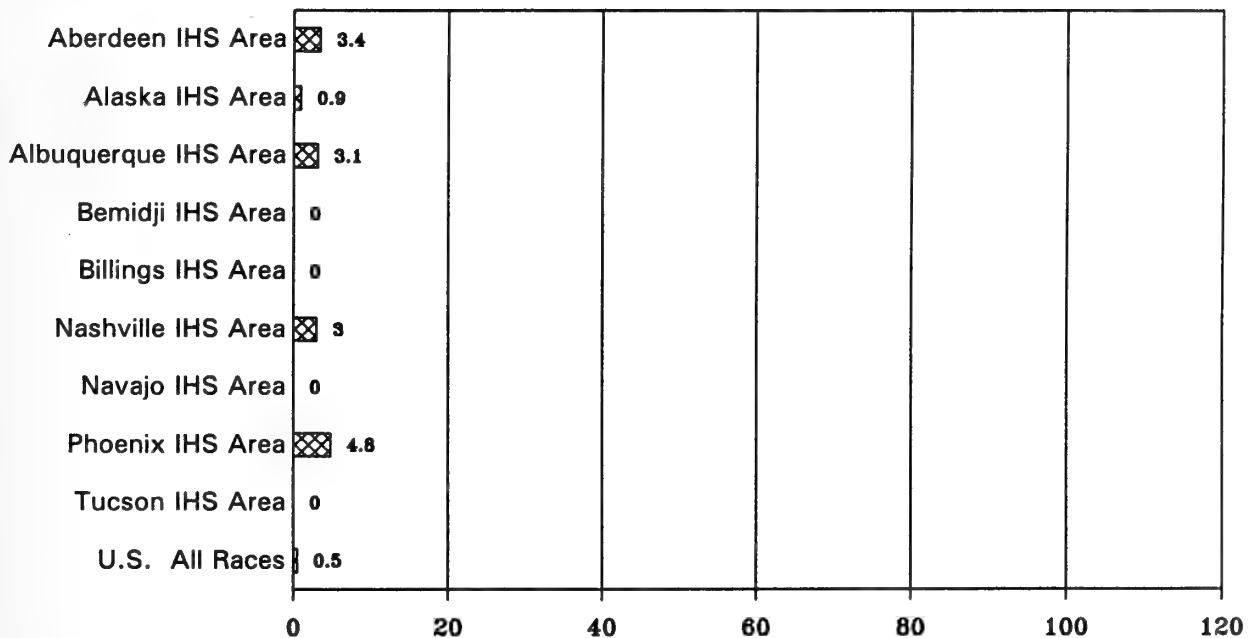




**Graph 4.27** Age-Adjusted (1970 U.S. Standard Population) Gallbladder Cancer Mortality Rates per 100,000 Population for IHS Areas, Females 1984-1988<sup>3</sup>



**Graph 4.28** Age-Adjusted (1970 U.S. Standard Population) Gallbladder Cancer Mortality Rates per 100,000 Population for IHS Areas, Males 1984-1988<sup>3</sup>



As with all cancer sites, there is variability among regions. Each of the IHS Areas has gallbladder mortality rates which are higher than the white rate (U.S. rate is 1.0). There is great variability among the IHS administrative areas. For example, the Tucson Area had the highest age-adjusted gallbladder cancer mortality rate for females which is 24 times the U.S. rate. In comparison, a few IHS Areas had rates which were higher than U.S., but quite low in comparison to Tucson, e.g., the Billings rate of 3.9.<sup>3</sup> Tribal data are not available.

There were no gallbladder cancer deaths reported in the Nashville IHS Area for either sex and there were no gallbladder cancer deaths reported for American Indian males living in the Tucson IHS Area.

### **Gallbladder Survival**

According to the New Mexico SEER which includes data on American Indians in Arizona and New Mexico, American Indians, both sexes, have a five-year gallbladder survival of 5.6 percent, which is the poorest survival of any racial group. The white survival for both sexes is 9.4 percent. American Indian males have the lowest survival of any racial group at 3.0 percent (white survival is 9.4 percent). American Indian females also have the poorest survival of any racial group at 6.4 percent (white female percent is 9.4).<sup>2</sup> Survival data for Alaska Natives are not available.

## **DISCUSSION**

### **Mortality Rates that are Higher than Incidence Rates**

Review of the site-specific incidence and mortality rates for specific tribal groups or IHS Areas occasionally indicate some illogical findings. For example, there are more lung cancer deaths (17.2) than incidence (6.3) for the American Indian males from the Phoenix IHS Area. The reason for this is not known. It is not uncommon for American Indians to migrate to their place of employment while maintaining their tribal residence. The individual who works elsewhere, may be diagnosed with cancer in another city or geographic region, and then return to the reservation when ill (i.e., to die at home in the presence of family and loved ones). The patient may have received their initial cancer diagnosis from third party payment as part of their employment benefits, which would not show up in IHS hospital records. The Native American patient may have never seen a physician to receive a diagnosis. The data may also have coding errors. It may be that all of these speculations exist. Nonetheless, those data should be examined carefully.

### **"Burden of Disease"**

When data are age-adjusted, they allow for comparisons among groups without bias due to age structure of the population. This age-adjustment assists in prioritizing specific cancer sites within a group of peoples. However, age-adjusting the data may camouflage the burden of disease upon the family and community. Cancer incidence and prevalence increases with age and occurs more often in older individuals and elders. The many ways that the disease affects a community -- particularly when the most common patients are elders--needs to be recognized. The burden of these diseases is magnified when poverty exists in both the family and the community. Cancer prevention, control and treatment programs need to provide

appropriate support to manage the burden of this disease within poor, underserved communities.

### **Research Studies with Small Populations**

The number (i.e., "n") of cancer patients and people at risk is small for all Indigenous groups, e.g., American Indians, Alaska Natives, Native Hawaiian and American Samoan. Some scientists hesitate to invest time working with small groups of people in cancer research because of the limitations which occur with small sample and population sizes. Among the challenges of working with a small "n", is that the statistical tests have less power. A difference may *not* be statistically significant because the sample was too small to show that difference exists. This does not mean that there is no effect; it means that the calculations failed to demonstrate the existence of one.

Regardless of the small size, it is important to study small population groups. Factors may be learned by working with smaller size populations that can be of assistance to people of all races. For example, American Indian women living in the Southwest do not appear to experience the same cervical cancer risk factors as do white Southwestern women. A study of the Indian women from this region may assist in identifying some unknown risk factor for cervical cancer that can exist in other populations as well.

In general, scientists prefer to work with large "n's": data analyses are well-defined. A population that is small in number, such as Alaska Natives or tribes in Florida, retain the right to have access to accurate data relevant to cancer incidence, death, survival, preventive measures and so on. The small numbers of Navajo uranium miners provided worthwhile lung cancer findings that have been generalizable to uranium miners, regardless of race.

Scientists need to determine some way to work with groups of small numbers. Small populations, like the Nez Perce, should be included in cancer prevention and control research studies to assist in reducing cancer deaths and preserve the cultures. In addition, cancers which have been very rare in the past, such as one case a year, and suddenly 3 or 4 are diagnosed in a year deserve concern. It does not matter whether that unusual cancer is in whites, blacks, Vietnamese, or American Samoans. Such a pattern change deserves investigation. Public policy decisions may need to be made based upon small numbers.

### **SUMMARY**

This chapter has included American Indian and Alaska Native data for specific cancer sites. The data illustrate the geographic and/or tribal variability that exists for each of the cancer sites. The challenge of using data from Indigenous Peoples of one region to generalize to another area is obvious. Based upon the regional data, it appears that cancer is more common in Alaska and in the Northern Plains, but geographic variations are observed for each of the eight cancer sites presented in this chapter.

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2. Department of Health and Human Services, PHS, NIH, NCI. Report of the Special Action Committee, 1992: Program Initiatives Related to Minorities, the Underserved and Persons Aged 65 and Over. Washington, DC: Government Printing Office. 1992, Appendix A.
3. Valway S, Kileen M, Paisano R, Ortiz, E. Cancer Mortality among Native Americans in the United States: Regional Differences in Indian Health, 1984-88 and Trends Over Time. Indian Health Service, Albuquerque, NM 1992.
4. O'Brien M. Urban Indian Health Comparative Analysis Report. American Indian Health Care Association, St. Paul Minnesota. 1992.

## CHAPTER 5. BRIEF REVIEW OF CANCER RISK FACTORS AND TOBACCO

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### CHAPTER OBJECTIVES:

- DEFINE RISK FACTORS AND EXPLAIN HOW THEY DIFFER FROM "CAUSES"
  - LIST, IN CHART FORM, RISK FACTORS FOR THE CANCER SITES WHICH ARE COMMON AMONG AMERICAN INDIANS AND ALASKA NATIVES
  - BRIEFLY DESCRIBE EXAMPLES OF RISK FACTORS FOR CANCER SITES WHICH ARE COMMON AMONG AMERICAN INDIANS AND ALASKA NATIVES
  - DISTINGUISH BETWEEN CHRONIC AND CEREMONIAL USE OF TOBACCO.
  - BRIEFLY DESCRIBE SELECTED SMOKING AND SMOKELESS TOBACCO USE STUDIES AMONG NATIVE AMERICANS.
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### INTRODUCTION

This chapter is limited to a very brief description of cancer risk factors. There is a dearth of data on cancer risk factors among American Indians and Alaska Natives. This chapter provides a chart (See figure V.1) which lists risk factors for the eight cancers which were described in Chapter Four. A brief description of smoking and smokeless tobacco use is included with this chapter. Dietary factors are described in greater detail in Chapters 6, 7, and 8.

Specific data related to Native Americans are currently being collected through pre- and post- intervention surveys as part of the on-going Native American cooperative agreements. Those data are tentatively scheduled to be released during fiscal year 1995.

For further information on risk factors, the reader is referred to the NCI Office of Cancer Communication's Cancer Information Services (CIS) [telephone number 1 (800) 4-CANCER, or 1 (800) 422-6237]. For example, a 1985 publication which provides a comprehensive overview of risk factors is *Cancer Rates and Risks* (NIH Publication number 85-691). The CIS can also provide a listing of additional resources.

The American Cancer Society also produces booklets and pamphlets on risk factors. An excellent resource is *Cancer Facts and Figures - 1993* which is published each calendar year by the American Cancer Society. Another resource from ACS is *Cancer Risk Report: Prevention and Control 1992*. *Cancer Facts and Figures for Minority Americans 1991* has limited information about Native Americans, but does provide some data for other underserved populations.

Publications of Doll and Peto, e.g., "The causes of cancer: Quantitative estimates of avoidable risks of cancer in the United States today",<sup>1</sup> are highly recommended reading.

Table 5.1 Summary Chart - Risk Factors for Specific Cancer Sites

Risk Factors	Breast	Cervix	Colo-rectal	Lung	Prostate	Gallbladder	Stomach	Pancreas
Habitual Tobacco Use		✓ <sup>1</sup>	✓ <sup>2</sup>	✓			✓	✓
High Fat/Calories	✓		✓		✓ <sup>1</sup>	✓		
Low Fiber/Fruits and/or Vegetables		✓	✓	✓	✓ <sup>1</sup>		✓	
Food Preservation							✓ <sup>3</sup>	
Alcohol misuse	✓		✓	✓	✓ <sup>1</sup>			
Multiple sexual partners		✓	✓ <sup>2</sup>		✓ <sup>1</sup>			
Menarche age 12 or younger	✓							
Early Age at First Coitus		✓						
Late Age (30+) at First Birth	✓		✓					
Diseases/Disorders	✓ <sup>4</sup>	✓ <sup>5</sup>	✓ <sup>6</sup>		✓ <sup>7</sup>	✓ <sup>8</sup>	✓ <sup>9</sup>	✓ <sup>10</sup>

<sup>1</sup> possible risk factor<sup>2</sup> risk for anal cancer<sup>3</sup> pickled, salted, smoked foods<sup>4</sup> Previous breast disease<sup>5</sup> Human Papilloma Virus (HPV), Herpes Simplex Type 2 (HPV)<sup>6</sup> Human Papilloma Virus (HPV) may be related to anal cancer; inflammatory bowel disease; polyps, clostridia, syphilis<sup>7</sup> Urinary tract infection<sup>8</sup> Biliary disease; gallstones, cholecystitis, ulcerative colitis<sup>9</sup> Pernicious anemia; atrophic gastritis<sup>10</sup> Diabetes

Risk Factors	Breast	Cervix	Colo-rectal	Lung	Prostate	Gallbladder	Stomach	Pancreas
Air Pollution				✓				
Chemical exposure (e.g., Occupational)			✓ <sup>11</sup>	✓ <sup>12</sup>	✓ <sup>13</sup>		✓ <sup>14</sup>	
Ionizing Radiation	✓		✓	✓ <sup>15</sup>			✓	
Socioeconomic	High	Low	Low	Low	✓ <sup>1</sup>		Low	
Genetics/Family History	✓ <sup>16</sup>	✓ <sup>1</sup>	✓		✓ <sup>1</sup>	✓	✓ <sup>17</sup>	
Increasing after age ____	30	50	50		65			30
Hormone(s)	✓	✓	✓		✓			
Other					✓ <sup>18</sup>			

<sup>11</sup> Asbestos

<sup>12</sup> Asbestos, arsenic, mustard gas manufacture, copper smelter workers, nickel

<sup>13</sup> Cadmium exposure; rubber industry

<sup>14</sup> Nitrosamines/nitrites

<sup>15</sup> Uranium mining; atom bomb survivors

<sup>16</sup> Mother or sister

<sup>17</sup> Blood Type A

<sup>18</sup> Geographic Distribution (higher rates in the North)

## Risk Factors and Carcinogens

"Cancer risk factors" refer to agents (e.g., high consumption of dietary fat) which, based upon scientific evidence, increase the likelihood of developing one or more types of cancer. In comparison, "carcinogens" include certain man-made and natural chemicals which cause cancer. For example, smoking and smokeless tobacco are carcinogens that cause changes that turn a normal cell into a cancer cell. (NIH Pub No. 87-2059) When exposed to a carcinogen, given enough frequency, duration and/or exposure to that factor, a specific type of cancer will eventually develop in most people. For example, chronic tobacco use causes nearly 90 percent of lung cancer. There are substantial data to support that chronic tobacco use has a causal relationship to cancer rather than only a "risk".

## A LIST OF RISK FACTORS FOR THE CANCER SITES WHICH ARE COMMON AMONG AMERICAN INDIANS AND ALASKA NATIVES

The chart (Table 5.1) on the previous pages is a quick reference and lists the eight cancer sites which were described in Chapter Four. Risk factors for those cancer sites are listed in the columns. Check marks indicate that the risk factor has been indicated for a specific cancer site. The footnotes provide brief clarification or qualification for the risk factors.

## TOBACCO

The hazards of habitual smoking and smokeless tobacco use are well documented in numerous publications. The reader who is interested in examining tobacco interventions or cessation programs is referred to the following Department of Health and Human Services publications, Government Printing Office, Washington, DC:

- NIH Publication number 92-3316, *Strategies to Control Tobacco Use in the United States: A Blueprint for Public Health Action in the 1990's.*
- NIH Publication number 92-3461, *Smokeless Tobacco or Health: An International Perspective. Monograph 2*
- NIH Publication number 90-3107, *Smoking, Tobacco and Cancer Program 1985-1989 Status Report.*

## Ceremonial Versus Habitual Tobacco Use

A distinction is made in this chapter between ceremonial and habitual tobacco use. Not all tribes include tobacco in ceremonies, but many tribal groups who use tobacco spiritually do not feel it should be discussed with habitual use/abuse of tobacco. Ceremonial tobacco use is briefly discussed to apprise the reader of the existence of these practices. Specific ceremonies are not described. Native Americans reserve the right to privacy regarding the ceremonial use of tobacco. Ceremonial tobacco use varies greatly among tribes.

A tobacco prevention and cessation program which is targeted to Native Americans needs to be sensitive to the possible inclusion of tobacco within the culture and health mandates likewise require adaptation. For example, rather than mandating, "no tobacco use", a modification may be, "no habitual tobacco use" or something similar.



The mandated message of no tobacco use results in confusion among many Native Americans. For example, Native youth who are exposed to educational programs in schools which espouse no tobacco use, observe grandparents or other respected members of the community using tobacco in ceremonies. Or, another source of confusion which may impact accurate data collection is tobacco use survey items. An item such as, "Do you use tobacco?" may receive a "yes" response from an individual who participates in ceremonies where tobacco is used, but may not use tobacco habitually.

There are a lack of studies which have examined ceremonial use of tobacco. There are several reasons for this. The major reason for this is that it is inappropriate for Native Americans to discuss the use of tobacco as a sacrament. Native respondents to survey questionnaires and other inquiries are likely to refuse to answer or provide an inaccurate response. A second reason is that Indian people may call the sacrament, "tobacco," but in reality, a substance similar to tobacco, but a herb or another plant, may be what is actually being used. A third reason is that tribal ceremonies use *very small amounts* of tobacco and the exposure to tobacco infrequently for short duration. A fourth reason is that the tobacco is used in many different manners in ceremonies. Non-natives assume that it is always smoked in a pipe, but it may remain in a "crumbled" leaf form, or it may be included in a paste and spread upon the skin. It may be used in its seed form, such as sprinkled around young corn plants. Tobacco has many ceremonial uses.

### Smoking and Tobacco Use

The *habitual* use of tobacco is estimated to be responsible for about 30% of cancer in people of all races. Cigarettes are estimated to be responsible for over 400,000 deaths annually. Tobacco use is responsible for more than one of every six deaths in the United States and is the most important single preventable cause of death and disease in our society.<sup>2</sup>



Tobacco use is responsible for *causing* nearly 90 percent of all lung cancer.<sup>3</sup> Tobacco also causes cancers of the following sites: larynx, oral cavity, esophagus, bladder, kidney, pancreas, and stomach.<sup>4</sup> In addition, women who smoke may be at higher risk for developing cervical cancer than are non-smoking women.

Lung cancer incidence risk is proportional to the amount smoked daily and the duration of time smoked.<sup>2</sup> Lung cancer mortality increases with increasing doses, as determined by number of cigarettes smoked daily, smoking history, and inhalation patterns. Those who smoke two or more packs a day have death rates 15 to 25 times greater than nonsmokers. Cessation of smoking, though, reduces the risk of death from lung cancer; after 15 years, former smokers have lung cancer death rates only about two times greater than nonsmokers.<sup>2</sup> Those who smoke filtered, low-tar cigarettes gain some benefit, but they still have death rates much higher than nonsmokers. Lung cancer is rare in individuals who have never smoked. Cessation

of cigarette smoking results in a gradual decrease in lung cancer risk. After 10 to 20 years of cessation, lung cancer rates for former smokers approach the rates of lifelong nonsmokers.<sup>2</sup>

Lung cancer is exceptionally difficult to treat. Nearly 90 percent of lung cancer patients die within 5 years of diagnosis. Survival improves modestly when lung cancer is detected at an early, localized stage, but few cases are detected early. Prevention is the key to reducing lung cancer morbidity and mortality.<sup>2</sup>

American Indians and Alaska Natives do not have protection from developing lung or other types of tobacco-related cancers. Dr. Thomas Welty, Medical Epidemiologist for the Aberdeen Indian Health Service, South Dakota, stresses, "If Indians smoke, they get cancer just as other populations do."<sup>5</sup>

### **Smokeless Tobacco Use**

Smokeless tobacco includes moist or dry snuff and chewing tobacco. All smokeless tobacco products contain substantial amounts of nicotine. Smokeless tobacco use causes mouth and lip cancer. Smokeless tobacco use increases one's risk of developing leukoplakia, gingival recession and nicotine addiction.

### **LITERATURE RELATED TO REGIONAL TOBACCO USE VARIABILITY**

Researchers frequently state that American Indians have reduced mortality from lung cancer and other types of tobacco-related cancers. But statements such as that are based on Southwestern data which include populations whose practices include very low to no tobacco use.<sup>6</sup> Smoking and smokeless tobacco use varies among tribes, geographic areas, and living area (urban versus reservation).

The following section provides descriptions of selected articles which have focused on smoking and smokeless tobacco use among Native Americans. This section provides *examples* of the types of tobacco prevalence studies which have been conducted among Native American populations during the last few years. The articles are sequenced from most recent to oldest. The criteria for the selection of articles were that a substantial number of American Indian respondents were included in the study and the study reflects variable use patterns for different regions of the country. Based upon the limited information available, it appears that use of tobacco products is lower among Southwestern Indians and is higher in Native Americans living in the Northern Plains, Alaska, and urban areas.

### **Publications on Behavioral Risk Factor Surveys**

The Centers for Disease Control and Prevention collects data throughout the country utilizing the Behavioral Risk Factor Surveillance Survey (BRFSS). This survey includes tobacco use. Data were analyzed for 3102 American Indians and Alaska Natives from 47 states and the District of Columbia using a telephone interview protocol. During 1987-1991, the prevalence of smoking was higher among American Indian and Alaska Native men (33.4%) and women (26.6%) than among white men (25.7%) and women (23.0%). The average number of cigarettes smoked per day among smokers was lower for American Indian and Alaska Native men (19.4) and women (15.5) than for white men (21.4) and women (17.4).

The rate of smoking was substantially higher among college educated Native men (37.5%) than for college educated whites (14.6%).<sup>7</sup>

NOTE: Telephone surveys may not accurately reflect tobacco use prevalence among Native Peoples since many areas have little access to home phones. For example, in 1992, 74.6% of Peoples living in the Navajo IHS Area do *not* have a home phone. In seven of the IHS Areas, the percentage of homes which have *no* phone was greater than 42%.<sup>8</sup>

Sugarman and others (1992) utilized Behavioral Risk Factor Surveillance System (BRFSS) data for the period 1985-88. Those data were collected using the standard protocol of telephone surveys. Of the 1,055 Native American respondents, 32.7 percent (345) were from the Plains States. Current smoking was reported for Plains Indians for 48.4 percent of the Plains Indian men and for 57.3 percent of the Plains Indian women. Twenty percent (220) of the BRFSS respondents were Southwestern Indians. Of these, only 18.1 percent of Indian men and 14.7 percent of Indian women reported current smoking.<sup>9</sup>

Sugarman and others (1992) from 1987 to 1989, conducted behavioral risk surveys using many of the same questions in the BRFSS to selected tribes in Montana (e.g., Blackfeet, Chippewa-Cree, Assiniboine and Sioux). This was a collaboration with IHS and CDC. These surveys were conducted by trained Indian personnel who interviewed adult respondents in person. Of the 412 male respondents, 50.7 were current smokers and 19.2 were current users of smokeless tobacco. Of the 393 female respondents, 54.5 percent were current smokers and 1.5 were current smokeless tobacco users.<sup>9</sup>

Goldberg and others (1991) use face-to-face survey methodology to administer a behavioral risk factor survey throughout the Blackfeet Reservation and in metropolitan Great Falls using the Native American Center population records which included about 80-90% of resident Indians. The stratified sample included 116 reservation women, 125 Reservation men, 116 urban Indian women and 106 urban Indian men. The response rate for individuals selected from the Reservation was 81% and was lower for urban Indians (e.g., lowest rate was 62% for urban Indian males). The percentage of persons who reported smoking at least 100 cigarettes during their lifetimes ranged from 77% for Great Falls women and 75% for Great Falls men down to 63% for reservation women and 52% for reservation men. The prevalence of current cigarette smokers was 63% of Great Falls men, 62% of Great Falls women. Smoking prevalence in Great Falls respondents was at least 50% for each age and educational category for both men and women. The prevalence of current cigarette smoking for Blackfeet reservation was 34% for males and 50% for females.<sup>10</sup>

Welty and others (1987) summarized the results of various surveys on the prevalence of cigarette smoking among adult American Indians and Alaska Natives in the following table:

Table 5.2 Prevalence Surveys of Cigarette Smoking<sup>11</sup>

Population	Year Reported	Prevalence of Smoking	
		Total	Heavy <sup>1</sup>
<b>AMERICAN INDIANS AND ALASKA NATIVES</b>			
Northern Plains			
Sioux <sup>2</sup>	1984	42%	NA <sup>3</sup>
Cheyenne River Sioux <sup>4</sup>	1986	59%	NA <sup>3</sup>
Urban Indians	1984	70%	32%
Southwest			
Southwestern Indians	1968	21%	4%
Navajos	1979	13%	1%
Papagos (Tohono O'Odham) <sup>4</sup>	1983	28%	4%
Non-Southwestern Indians	1968	50%	26%
Alaska Natives	1983	56%	24%
<b>General Population</b>			
Men	1985	31%	21% <sup>5</sup>
Women	1985	28%	15% <sup>5</sup>

1 Heavy smoking = greater than 20 cigarettes daily

2 Study included only pregnant women

3 NA = not available

4 IHS unpublished data from household surveys; 159 Papago and 400 Cheyenne River Sioux

5 \*\*Prevalence for "heavy" smoking, as defined here (20+ cigarettes daily), is previously unpublished National Center for Health Statistics data.

### Urban Indians Cigarette Prevalence

Lando and others (1992) conducted personal interviews with a convenience sample in four urban Indian Health clinics: Milwaukee, WI, Minneapolis, MN, Seattle and Spokane, WA. Eligibility for the interview included the following requirements: at least 18 years of age; have smoked at least 100 cigarettes in their lifetime; and identify themselves as either American Indian or Alaska Native. Of the 592 participants, 419 were current smokers and 173 were ex-smokers. The median consumption was 11 cigarettes per day. The current smokers for the Minneapolis Clinic was 70.7% (n=157), for Milwaukee was 73.6% (n=129), for Seattle was 64.5% (n=155), and for Spokane was 74.8% (n=151). Significant differences were observed among the four clinic sites in age and sex. Minneapolis subjects were both younger and more likely to be female than were subjects from the other three clinics.<sup>12</sup>

### Selected Publications -- Native American Youth

Blum and others (1992) designed a survey on health risk behaviors, concerns and resiliency-promoting factors among American Indian and Alaska Native adolescents. A total of 13,454 seventh-through 12th grade Native American youths participated. The Minnesota Adolescent Health Survey was modified. The revision, Indian Adolescent Health Survey, was self-administered and included 162 items. Of the Native youths surveyed, 49.3% were male

and 50.7% were female. For every grade level after the seventh grade, females were more likely to be daily cigarette smokers than males, rising from 8.9% (358/4005) in junior high school to 17.8% (476/2673) in high school: the range for males was 8.1% and 15.0% respectively. Daily use of smokeless tobacco was consistently higher for males than females with 12.2% (480/3930) using smokeless tobacco in junior high school, rising to more than one in six by high school. For females, there was little variation, with 7.8% (311/4010) using in junior high school and 7.8% (209/2671) in high school.<sup>13</sup>

Beauvais (1992) compared the drug use rates of Indian youth living on reservations, Indian youth living off reservations and Anglo youth. The 1988-90 American Drug and Alcohol Survey was implemented and analyzed. For cigarette use, reservation youth have the highest rates (8th graders: 74%; n=638 and 12th graders: 80%; n=398), the rates for the non-reservation Indian youth are next (8th graders: 64%; n=942 and 12th graders: 71%; n=428) and the lowest rates occur for Anglo youth (8th graders: 46%; n=23,508 and 12th graders: 62%; n=25,183). For smokeless tobacco, reservation youth also have the highest (8th graders: 65%; n=638 and 12th graders: 74%; n=398), the rates for non-reservation youth are next (8th graders are 30%; n=942 and 12th graders: 43%; n=428), and Anglo youth was lowest (8th graders: 19%; n=23,508 and 12th graders: 34%; n=25,183).<sup>14</sup>

Bachman and others (1991) used questionnaire data from annual, nationally representative surveys of seniors from 1976 through 1989 to describe racial/ethnic differences in the use of licit and illicit drugs. The Monitoring the Future projected has survey large, nationally representative samples of high school seniors during the spring of each year since 1975. Approximately 130 high school participate each year (118 public and 12 private). The response rate averages about 83% yielding about 17,000 seniors each year. The 1976-79 sample included 563 Native Americans students; the 1980-84 sample include 933 Native Americans and the 1985-89 included 1068 Native Americans. In response to the survey item on use of cigarettes within the last 30 days, Native American positive responses included 36.8% (n=537) for males and 43.6% (n=531) for females. In response to the survey item of using half of a pack of cigarettes or more per day, the Native American responses include 18.4% (n=537) for males and 23.4% (n=531) for females. The half-pack daily use is highest among Native American seniors. It is speculated that the rates may actually be higher than those reported due to the very high dropout rates among Native Americans.<sup>15</sup>

The Great Alaska Spit-Out Tobacco Use Survey (1990) was completed by 1,555 school children in Alaska. The prevalence of tobacco use included 28.4% use of some type of tobacco; 16.4% used cigarettes and 16.4 used smokeless tobacco. The youngest user was 7 years old. Half of the users (53.6%) reported using tobacco 2-3 times per day while an additional 33.7 percent reported using 5-10 times per day. Only 2.7% of the tobacco users reported using more than 20 times a day. Tobacco use was highest in the following regions: Norton Sound, YK, Ketchikan, TCC, and Manillaq. The prevalence of smokeless tobacco use was highest in YK region followed by Norton Sound, and TCC.

### **Selected Smokeless Tobacco Use Prevalence Studies**

Sugarman and others (1992) utilized Behavioral Risk Factor Surveillance System (BRFSS) data for the period 1985-88 (study was described earlier). Smokeless tobacco items for American Indian respondents from each region of the country were summarized. The

smokeless tobacco use was 9.3 percent ( $n=54$ ) for Southwest (e.g., Arizona, New Mexico, Utah) respondents, 14.5 percent ( $n=92$ ) for Northern Plains (e.g., Iowa, Minnesota, Montana, Nebraska, Dakotas) respondents, and 1.9% ( $n=46$ ) for West Coast (e.g., California, Washington, Idaho) respondents.<sup>9</sup>

Bruerd (1990) reviewed seven published and two unpublished surveys of Native American school children's use of smokeless tobacco (ST). All included survey items on current ST use although it was interpreted in one of two ways. Five studies defined "regular ST use" as those who "use now" and four studies defined "regular ST use" as "use weekly. There were significant differences among current users by geographic regions, with prevalence lowest in the Northeast and highest in the South. In all nine studies a total of 9,220 Native American school age children responded to questions about ST, including items on current ST use. The difference in ST use between reservation-based Indians and urban Indians was not statistically significant ( $P = .16$ ). Specific numbers of doses per day or week were not uniformly collected. Prevalence of regular ST use ranged from 18 percent in K-6th graders to 55.9 percent in 9th and 10th graders. ST use increased with grade and age. On the reservation where 18 percent of the K-6th graders used ST, use among 7th-12th graders was 37 percent. The Alaska study showed significantly different rates for boys ( $n=2,511$ ; 33.7%) and girls ( $n=2,454$ ; 27.5%).<sup>16</sup>

Beauvais and others (1989) examined trends of drug use among Indian youth through analysis of a self-administered, anonymous questions which has been adapted for Indian youth. The survey has been administered since 1975. Five to six tribes are selected each year to yield an annual sample of 1,000 to 2,000 youth. In the 1984-85 sample ( $n=1510$ ) 79% reported lifetime use of cigarettes. In the 1986-87 sample ( $n=2683$ ), 78 percent reported cigarettes use and 58 percent reported smokeless tobacco use. Of the 325 "lifetime users", 38.3% indicated that they had smoked cigarettes within the last month and 31.4% had used smokeless tobacco within the last month.<sup>17</sup>

Hall and Dexter (1988) conducted a survey of 1,180 sixth, ninth and eleventh graders in the State of Washington. The Northwest Portland Indian Health Board contracted with staff at the Oregon State University to survey school-aged youth in three school districts where Native Americans comprise a significant number. Prevalence of current ST use among Native Americans included 34% ( $n=137$ ) for males and 24% ( $n=120$ ) for females. In comparison the prevalence of current ST use among non-natives was 20% ( $n=438$ ) for males and 4% ( $n=415$ ) for females.<sup>18</sup>

## CIGARETTES AND ALCOHOL

Prevention of alcohol abuse is high health priority among Native American communities. In studies with other races, alcohol combined with cigarette use presents a risk for cancer. Alcohol is a powerful solvent and may enhance body absorption of carcinogens. Epidemiologic data indicate that the combination of chronic alcohol consumption and tobacco use substantially increases the risks of cancers of the oral cavity, esophagus and pharynx, though probably not of the lung.<sup>19</sup> No alcohol-cigarette use studies have been conducted with Native Americans.

## DISCUSSION

### Smoke Shops

Tobacco Smoke Shops exist on some reservations. Tobacco and tobacco-related products are sold, usually tax-free, to customers. A portion of the profit from the sell of these tobacco products may be used as income to support the local Tribal Council and Tribal governments. Researchers who are attempting to work with reservations on tobacco prevention and control projects should be apprised of the existence of Smoke Shops prior to meeting with members of Tribal Council. The possibility that these profits from tobacco sales may be a source of income for the tribe are likely to influence the Tribal Council's enthusiasm for participating in tobacco prevention and control projects. Not all Smoke Shops provide income to tribal government, however, and many reservations have closed Smoke Shops in recent years.

### Increasing Cancer Rates among Indigenous Peoples

Many American Indian and Alaska Native communities have expressed concern over their perception that cancer is increasing among their peoples. This concern has been reflected in the increase in cancer topics included on Native American meeting and conference agenda from 1987 to 1993. The perception appears to be accurate but data need to be improved to accurately provide trend information.

There are few data available about indigenous people prior to the 1900's which include detailed information about the health and well-being of the populations other than missionaries reports, explorers' logs, settler's letters, and so on. Bureau of Indian Affairs records are very inconsistent and minimal information related to cancer or cancer risk factors can be gleaned from these documents. Review of the limited documents available indicate that cancer was a rarity among indigenous peoples. One reason for the exceptionally low rates is that people were dying from infectious diseases as well as other maladies and cancer is primarily a disease of the older individual.

Low or lack of participation in screening programs is another reason for minimal cancer rates recorded among Native people. Unfortunately, most Native people today are diagnosed after cancer has spread beyond effective treatment or cure. However, as American Indians and Alaska Natives begin to participate in cancer screening programs (e.g., annual pap smears), a sharp increase in the statistical *incidence* of cancer is frequently noted. This increase may reflect an increase in screening and identification of early stage cancers that are curable.

With today's medical technology, many cancers that are detected in the early stages of development can be cured or prevented by practicing healthy habits. Unhealthy life-style practices, such as chronic tobacco use, excessive use of alcohol, excessive intake of foods high in fat and low in fiber, minimal intake of fruit, vegetables and grain foods, and limited daily exercise are the lifestyle factors which each individual can control. These factors significantly contribute to the increased cancer rates. For a variety of reasons, the traditional



eating and exercise patterns of American Indians, Eskimos, and Aleuts were healthier than the lifestyles practices of today's Native people.

## SUMMARY

It is not known if the cancer risk factors for Native Americans differ from those of the U.S. population in general, but limited data indicate that further research is needed in this area. Preliminary data specific to American Indians and Alaska Natives will be available within the next few years.

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# SECTION II

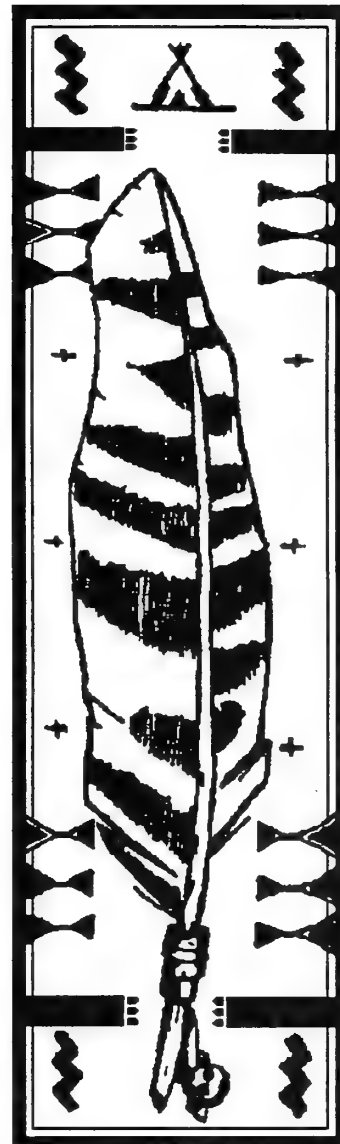
## DIET, NUTRITION, AND CANCER

### Target Audience

Section II of *Documentation of the Cancer Research Needs of American Indians and Alaska Natives* emphasizes the role of nutrition in cancer prevention and control. This section is primarily designed for use by 1) Native American researchers new to the field of cancer prevention and control, 2) non-Native researchers conducting such studies among tribal communities, and 3) individuals responsible for developing and designing diet and cancer prevention and control research proposals, programs, interventions, or educational materials. This includes, but is not limited to, tribal health planners, health educators, public health nutritionists, community health representatives, and health care providers at urban and rural Indian clinics.

### Purpose

Cancer mortality rates among American Indians and Alaska Natives have continued to increase since the turn of the century. However, few studies have collected the types of information needed to determine why these rates have increased, especially among some tribes but not others. The purpose of Section II is to provide users with 1) references of competent research that indicate the appropriate nutrition information to collect in cancer studies, 2) an overview of recent dietary recommendations and guidelines for eating a healthful diet to prevent certain cancers and chronic diseases, 3) what is known about the traditional and contemporary food consumption practices of Native People, 4) what diet and cancer research studies have been conducted with Native Americans, and 5) what are the surveillance and nutrition research needs to reduce their cancer mortality rates.



This Section is not meant to be an exhaustive scientific review of diet and cancer. Rather, it provides background information for users to:

- . document the need for diet and cancer prevention and control studies, programs, interventions, or educational materials.
- . identify data collection needs.
- . develop culturally appropriate data collection instruments.
- . identify dietary practices among tribes that promote or prevent cancer.
- . identify behaviors or factors that are motivators of or barriers to successful dietary interventions.
- . develop culturally sensitive cancer prevention and control materials and programs.
- . develop diet and cancer interventions in urban, rural and/or reservation settings.

To expedite these endeavors, Chapter 6 provides the user with an overview of the role of diet in promoting or preventing the cancers common among Native Americans, a reevaluation of the 1982 Diet, Nutrition, and Cancer recommendations, and listings of food consumption and cancer research references and dietary components and cancer research references.

Chapter 7 provides the recent dietary recommendations of three recognized health authorities, background on the traditional consumption practices of Native Americans, factors that have impacted on their health and nutritional status, their contemporary nutrition-related health concerns, and what is known about their contemporary consumption practices and whether these practices meet the dietary recommendations.

Chapter 8 summarizes the cancer surveillance and data needs and the diet and cancer research needs that are necessary to reduce the cancer mortality rates of Native Americans, and examples of projects and activities sponsored by the National Cancer Institute that focus on improving the health and nutritional status of Native Americans.

The Special Populations Studies Branch of NCI has planned to publish a bibliography of Native American cancer and cancer-related literature. However, the publication will not include dietary references. Thus, the bibliography listings included in Chapter 6 are extensive, but not exhaustive of the diet and cancer literature and Appendix "F" includes food, nutrition, and cancer publications specific to Native Americans.

## CHAPTER 6. NUTRITION'S ROLE IN CANCER PREVENTION AND CONTROL

- 
- *PROVIDE AN OVERVIEW OF THE ROLE OF DIET IN PROMOTING OR PREVENTING CANCER.*
  - *PROVIDE A REEVALUATION OF THE 1982 DIET, NUTRITION, AND CANCER RECOMMENDATIONS.*
  - *PROVIDE DIET AND CANCER RESEARCH REFERENCES AND DIETARY COMPONENT AND CANCER RESEARCH REFERENCES FOR RESEARCHERS INVESTIGATING THE RELATIONSHIPS OF DIET AND CANCER AMONG NATIVE AMERICANS.*
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### DIET AND CANCER: AN OVERVIEW

During a human's lifetime, the cells in the body divide approximately 10 trillion times. Precise systems preserve the body's health by 1) *regulating cells that normally divide throughout adult life*, such as bone marrow cells and the epithelial cells of the gut and skin; by 2) *preventing certain cells from dividing*, such as neuron and striated muscle cells, and by 3) *permitting the rapid regeneration of tissue cells that have been damaged*. Cancer occurs when cells escape these norms and acquire the ability to multiply and spread without the normal restraints.<sup>1</sup> The occurrence of this malfunction has continued to rise during the last two decades and is responsible for approximately 24%<sup>2</sup> of all deaths in the United States today.

After years of research and numerous experiments on tissue development and regeneration, it is known that local signals pass between cells, and that this network of signals serves to maintain the stability and integrity of each organ and tissue, and to protect the organism from any form of uncontrolled growth. Although these signal systems are not totally understood and it is not known how a cell must be altered to prevent it from forming a tumor, it appears that the different forms of uncontrolled growth leading to benign and malignant tumors have distinct causes. The pathological classification of all growth abnormalities depends on (1) the tissue of origin, (2) the type of cell division, and (3) most importantly, whether the abnormal cells are confined to their original location (benign) or have invaded the surrounding tissues or metastasized to different sites. An average cancerous growth is thought to arise from the proliferation of a single altered cell which will amount to many millions of cells before it becomes detectable. Cancerous growths are categorized as *carcinomas* that arise from an increase of epithelial cells; *lymphomas* resulting from an increase in circulating blood cells; and *sarcomas* that arise from increased cells in fibrous connective tissue or bone.<sup>1</sup>

## Causes of Cancer

Findings from extensive environmental, genetic, epidemiological and laboratory studies suggest that most cancers common to affluent industrialized nations have external causes, and, to a great extent, are preventable. For example, cigarette smoke is associated with bronchogenic carcinoma of the lung as is asbestos with mesotheliomas/bronchogenic carcinomas and certain aniline dyes with bladder cancer. However, it seems that most cancers common in the United States are not attributable to industrialization but rather to various other related long-standing features of lifestyle habits. Cancer research has shown that differing life-styles and acculturation do play an important role in acquiring certain cancers. Influential factors include the air breathed, the water drunk, food preparation habits, and food consumption. While most of these variables can be measured, direct correlations between diet and cancer have often been difficult to prove.<sup>1</sup>

Because nutrition is an integral part of health, physiology, and longevity, it is natural to suspect that it has a role in acquiring or preventing cancer. This hypothesis has been examined in both laboratory and epidemiological studies. Epidemiologists have found it relatively easy to demonstrate a correlation between the diets consumed by modern affluent societies and the consequences of cancers in such organs as the breast, colon, and uterus. However, determining which, if any, of the dietary components are responsible for promoting or preventing certain cancers has been a complex task.<sup>1</sup> Collecting specific and accurate information about what individuals eat is difficult, and assessing past eating habits which presumably initiated cancers is almost impossible. However, it is feasible to monitor the consumption practices of groups to develop profiles for studying the relationships between consumption patterns and known diseases or health conditions.<sup>3</sup>

## Diet: Its Relationship to Disease

In the past, some scientists believed the typical American diet eaten over a long period of time was a risk factor for the development and progression of certain chronic diseases. However, during the last two decades, ample scientific evidence has implicated dietary patterns (foods and beverages) as either protective or as risk factors in several of the leading causes of death in the United States- coronary heart disease, some types of cancer, stroke, noninsulin-dependent diabetes mellitus, cirrhosis of the liver, and atherosclerosis.<sup>4-7</sup> Specifically, in the 1989 report, *Diet and Health: Implications for Reducing Chronic Disease Risk*, a 19-member committee appointed by the Food and Nutrition Board of the National Academy of Sciences,<sup>6</sup> reviewed and evaluated the scientific evidence relating food intake to the maintenance of health and to the reduction of risk of chronic diseases. They concluded that:

- dietary patterns are important factors in the onset of dental caries, and chronic liver disease, and in the etiology of several major chronic diseases including atherosclerotic cardiovascular diseases, hypertension, and cancer of the esophagus, stomach, large bowel, breast, lung, and prostate.
- the mechanisms of nutritional, genetic, and environmental factors and their interactions in these diseases are not fully understood.

it is evident that *dietary modification can reduce the risk of developing chronic diseases*.

The Committee also emphasized that populations which consume excessive amounts of food or alcohol and do not routinely exercise generally have problems with obesity and chronic disease, the severity of which differs by age, sex, and heredity. Moreover, people with multiple risk factors generally have a greater chance of developing a health problem or chronic disease than people who have an absence of risk factors. Although scientists are not sure how the mechanisms of nutritional, genetic, and environmental factors interact in every disease, it is known that positive dietary and life-style changes can reduce the risk of developing health problems and chronic diseases.

### How Eating and Habits Can Cause or Prevent Cancer

Most of the body is made of water and held together by cellular structures of tissues, bone, teeth, muscles, nerves, hair and skin. Chemically, the body is made of oxygen (65%), carbon (18%), hydrogen (10%), nitrogen (3%) and minerals (4%). Vitamins, hormones, and enzymes influence movement, thinking, digestion and other bodily functions. Functionality depends on how well the cells are nourished. Energy is provided by foods rich in carbohydrates (starch & sugars), proteins, and fats; and minerals provide the body with a strong structural frame. A healthy, active body is produced when a *balance* of water, amino acids (proteins), fatty acids (fats), sugars, minerals, and vitamins are utilized from the foods eaten. An *imbalance or illness* results when diminished or excessive intakes of nutrients occur for prolonged periods of time. For example, limited intakes of iron generally result in iron deficiency anemia; moreover, overconsumption of calories will promote overweight, obesity, and eventually some form of chronic disease.<sup>1</sup>

In the early stages of cancer, a human is exposed to a mutagen or initiator that interacts in each cell with the DNA (deoxyribonucleic acid) which carries genetic information. Most carcinogenic initiators (a substance or agent that can start the process of carcinogenesis) created within the body result from *metabolic activation*. Most foods consist of a mixture of chemicals, some of which have specific nutritional functions. However, other chemicals in foods can act as cocarcinogens or as anticarcinogens by stimulating or inhibiting one of the enzymes involved in the metabolism of a carcinogen. Some non-nutritive constituents in foods have been implicated in the causation or prevention of cancers.<sup>1</sup> Researchers began to relate diet with cancer about 15 years ago. Wynder and Gori (1977)<sup>8</sup> estimated that diet was responsible for 60% of cancers in women and 30-40% of cancers in men. Later Doll and Peto (1981)<sup>9</sup> attributed approximately 35% of all cancer mortalities in the United States to diet. Since then, our knowledge about relationships between dietary factors and specific cancers has increased (Tables 6.1-6.10).

A variety of foods eaten in moderation will not cause cancer. However, in a 1987 review of the literature on caloric intake, body weight, and cancer, Albanes<sup>10</sup> indicated that a large number of epidemiological investigators found an association of high relative body weight and high caloric intake with an increased risk of cancer of the breast, colon, rectum, prostate, endometrium, kidney, cervix, ovary, thyroid, and gallbladder. Although the relationships among caloric intake, dietary macronutrients, (e.g., fat), and body weight are complex and require further investigation, Albanes' review suggests that *reducing caloric*

*intake and relative body weight may lead to a considerable decrease in cancer risk in humans. In laboratory studies on mice with multiple tumors, Albanes also indicated that total caloric intake was an important determinant of tumorigenesis, and that body weight may be a more sensitive indicator for this effect than is caloric intake alone.*<sup>11</sup> These findings, among others, implicate obesity as a potential risk factor for the development of cancer.

To prevent obesity or maintain a healthy body weight, some form of exercise is necessary. There is now ample evidence of the multiple health benefits of regular physical activity and how it helps to prevent obesity and several of the major chronic diseases, such as coronary heart disease, and diabetes.<sup>12</sup> Regular physical activity has also been associated with lower rates of colon cancer.<sup>13</sup> Studies have shown that, on the average, physically active people outlive those who are inactive,<sup>14</sup> and regular physical activity can help to maintain the functional independence of older adults, and enhance the quality of life for people of all ages.<sup>15</sup>

### **Reevaluation of the 1982 Diet, Nutrition, and Cancer Recommendations**

Given new knowledge from intensive research, the Council on Scientific Affairs of the American Medical Association (AMA) recently reevaluated whether or not the recommendations in the 1982 Diet, Nutrition, and Cancer Report<sup>1</sup> should be maintained or modified.<sup>16</sup> The AMA Council concluded the following.

*Recommendation 1: Reduce intakes of both saturated and unsaturated fats, from 40% to 30% of total calories.*

Regarding this recommendation, the Council stated that numerous animal experiments had indicated "that the cancer-enhancing property of dietary fat is the result of two effects: a general effect of excessive calories, and a specific effect due to the essential fatty acid, linoleic acid."<sup>17,18</sup> Limiting caloric intake reduces the risk of virtually all types of cancer in laboratory animals; however, the mechanisms involved are unclear. Although this fat/cancer link has been more difficult to establish in humans, epidemiological studies suggest that body size and mass and the lack of regular exercise may be related to the risk of breast cancer<sup>19,20</sup> and colon cancer.<sup>21</sup> The Council commented that other investigators also stressed the need for eating in moderation and engaging in regular physical activity.

*Recommendation 2: Include fruits, vegetables, and whole-grain cereal products in daily diet, especially citrus and carotene-rich and cabbage family vegetables; avoid high-dose supplements of individual nutrients.*

The second recommendation of the 1982 Diet, Nutrition, and Cancer Report encourages the consumption of foods known to contain substances that inhibit cancer in animal studies.<sup>22</sup> The Council stressed that the findings of several epidemiologic studies conducted since this report reinforce the conclusion that fruit and vegetable consumption is linked to the reduction of cancer risk (Chapter 6: Dietary Components and Cancer Research References). They concluded that it was important to eat a variety of these foods since the protective effect may result from a synergistic combination of substances in these foods.



*Recommendation 3: Minimize the consumption of cured, pickled, and smoked foods.*

The Council commented that this recommendation has proven to be confusing to consumers. Given the types of food preservation methods used in the United States today, it may be unnecessary to recommend that the general population reduce their consumption of commercially cured, pickled, and smoked foods. However, they emphasized that cultures with high death rates from stomach cancer tend to eat these foods daily.

*Recommendation 4: Drink alcohol only in moderation.*

With regard to the fourth recommendation, the Council emphasized that recent studies have shown that alcohol consumption, which generally means extra calories,<sup>20</sup> is positively associated with an increased risk of breast cancer.<sup>23</sup> Therefore, it would be prudent for those who drink alcohol to do so in moderation.

The overall conclusions of the AMA Council were that laboratory and epidemiological research provide no simple answers about the relationship of diet to cancer. However, "the key to the relationship ... may lie in nutrient interactions and in individual response to dietary factors, determined in turn by genetic, physiologic, and life-style factors." Thus, it may be that in the future individualized interventions in dietary and life-style changes will be necessary to maximize health and nutritional status. In the interim, the public is advised to eat and drink in moderation and increase the consumption of fruit, vegetables, cereal and fiber, and decrease total fat intake.<sup>24</sup>

The following publications have summarized reviews of the diet and cancer literature that substantiate the Council's conclusions. Miller's (1990)<sup>25</sup> review of the diet and cancer literature states that while inconsistencies existed in epidemiological, analytical, descriptive human and animal studies, *diets high in fat* are a major risk factor for breast, colorectal, and prostate cancers; *obesity* is an important risk factor for endometrial cancer and increases the risk of breast cancer in postmenopausal women but is protective in premenopausal women; and the *protective substances in foods rich in beta-carotene* may be components other than beta-carotene. Saracci's (1990)<sup>26</sup> review of the current trends in diet and cancer hypotheses provides further evidence of an association between carcinogenicity for several cancers and *alcohol intake*, and the relationships between *obesity* and cancers of the endometrium and gallbladder. In 1991, Weisburger<sup>27</sup> reemphasized the association of 1) *excessive intakes of salted, pickled or smoked foods* and the occurrence of hypertension/ stroke, and stomach cancer- the underlying mechanisms and relevant carcinogens for which are still only partially known, and 2) *of routine intakes of high-fat, low-fiber food* and increased risk of colon, pancreas, breast, prostate, ovary and endometrial cancer, and 2) high intake of vegetables and fruits and lower risk for diverse types of cancer.

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## DIET AND CANCER REFERENCES

The diet and cancer references are provided in two sections. *Section 1* includes tables that cite scientific literature (1961-1993) on epidemiologic studies that addressed the associations of diet to specific cancer sites. The table references are followed by reviews, critiques, and other pertinent diet and cancer literature; articles on Native Americans that address diet and cancer are provided where available. *Section 2* includes a listing of epidemiological and laboratory studies (1980-1991) that have examined the relationships of specific dietary components to cancer.

Although efforts have been made to include the most recent publications, these listings are not all inclusive of the research published on diet and cancer, nor has the National Cancer Institute judged these papers to provide persuasive evidence for putative diet-cancer associations. The interpretation of these publications is the sole responsibility of the investigator.

The references for the introductions to each of the following tables are:<sup>1</sup> Cancer Rates and Risks, 3rd. US DHHS. PHS, NIH Pub. No. 85-691. 1985; and <sup>2</sup> Diet, Nutrition, and Cancer. Committee on Diet, Nutrition and Cancer. National Research Council, National Academy of Sciences. Washington, DC. National Academy Press. 1982.

### SECTION 1. FOOD CONSUMPTION AND CANCER REFERENCES (1961-1993)

Table 6.1 BODY WEIGHT AND CANCER REFERENCES

Cancer	References
Breast	1964:deWaard et al 1969:Valaoras et al 1971:Mirra et al; Lin et al 1977:Adami et al; Soini 1978:Hirayama; Choi et al 1980:Paffenbarger et al 1981:Kelsey et al 1984:Brisson et al 1990:Ballard-Barbash et al 1992:Kato et al; Pathak & Whittemore; den Tonkelaar et al
Kidney	1974:Wynder 1984:McLaughlin et al 1986:Goodman; Yu et al
Endometrium	1982:Kelsey et al 1983:Henderson et al 1984:La Vecchia et al
Colon	1992:Thun et al

**Table 6.1 References: Body Weight and Cancer**

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## DIET AND BREAST CANCER

In America, breast cancer is a major cause of death among women. Studies have found that the risk of breast cancer is increased when a woman has a close relatives with breast cancer, children later in life, no biological children, early onset of menstruation and late menopause, benign fibrocystic breast disease confirmed by biopsy, been exposed to large dosages of radiation, a high socioeconomic status or uses estrogen replacement. Obesity caused by a diet high in calories, fat, and possibly alcohol also increases the risk of breast cancer.<sup>1,2</sup>

**TABLE 6.2 DIET AND BREAST CANCER REFERENCES**

Dietary Components	References
Total fat intake	1966:Lea 1968:Carroll et al 1970:Hems 1973:Drasar & Irving 1975:Armstrong & Doll; Carroll & Khor 1977:Knox 1978:Miller et al; Hems 1979:Gray et al 1980:Carroll 1981:Ingram; Kolonel et al 1986:Rose et al; Lubin et al 1987:Willett et al(a) 1990:Ewertz & Gill; Knekt et al 1991:Graham & et al; Howe et al 1992:Graham et al; Kushi et al; Willett et al 1993:van den Brandt et al
Fats: animal sources	1973:Drasar & Irving 1979:Gaskill et al 1980:Carroll 1981:Kolonel et al 1982:Kinlen 1984:Talamini et al 1986:Le et al; Hislop et al; Rose et al 1991:Lee et al; Zaridze et al 1992:Kato et al
Frequent consumption of high fat foods	1975:Phillips 1981:Lubin et al 1984:Kalamegham & Carroll 1992:Kato et al
Saturated fat	1985:Howe 1987:Hirohata et al 1990:Howe et al
Vegetable fat	1975:Phillips 1978:Enig et al; Nomura et al

Dietary Components	References
High animal protein intake	1973:Drasar & Irving 1975:Armstrong & Doll 1978:Nomura et al; Hirayama 1979:Gray et al 1981:Ingram; Kolonel et al; Lubin et al 1986:Rose et al; Hislop et al; Lubin et al 1991:Lee et al; Richardson et al
Alcohol	1982:Byers & Funch 1983:Begg et al 1984:Hiatt & Bawol 1986:Le et al 1987:Schatzkin et al; Willett et al(b) 1990:Nasca et al; 1991:Zaridze et al; Ewertz; Ferroni et al; Simon et al; Steinberg & Goodwin 1992:Gapstur et al
Carbohydrate or fiber sources	1982:Adelcreutz et al 1986:Lubin et al 1990:Van't Veer et al 1992:Graham et al; Willett et al 1993:Rohan
Vegetables	1990:Ewertz & Gill 1992:Kato et al
Carotene, retinol	1991:Graham et al 1992:London et al
Vitamin A	1992:Graham et al 1993:Rohan et al
Soy products	1991:Lee et al
Fruits & vegetables	1990:Howe et al
Vitamin C intake	1990:Howe et al 1992:Graham et al 1993:Rohan
Vitamin E	1992:Graham; London et al 1993:Rohan

Table 6.2 Diet and Breast Cancer References

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## DIET AND COLORECTAL CANCER

The colon refers to the upper 5-6 feet of the large intestine; the rectum- the last 5-6 inches. Risk factors vary for the two cancers. Colorectal cancers caused an estimated 58,000 American deaths in 1983. For the general population, death rates are highest among persons living in the Northeast and lowest in the South and Southwest. The incidence of colon and rectal cancers increases sharply after age 50 and dramatically after age 75 years, when there is a family tendency to develop colon polyps, when there is a history of inflammatory bowel disease, and if one lives in urban, industrialized areas rather than in rural areas. Both genetics and environment are believed to be responsible for colon and rectal cancers.

With regard to diet, there are three hypotheses that appear to be supported by data of various strengths obtained from epidemiological studies of both colon and rectal cancer: 1) an association with total, and perhaps saturated, fat; 2) a protective effect of dietary fiber (fruits, vegetables and whole grain foods); and 3) a protective effect of cruciferous vegetables (Chapter 7:Table 7.2). The possible role of alcohol and rectal cancer requires further study.<sup>1,2</sup>

**TABLE 6.3 DIET AND COLORECTAL CANCER REFERENCES**

Dietary Components	References
Alcohol (especially with rectal cancer)	1978:Bjelke 1979:Dean et al 1984:Pollack et al 1986:Kabat et al 1987:Kune et al 1991:Hu et al; Kune et al 1992:Arbman et al
Total fat intake	1973:Drasar & Irving 1975:Armstrong & Doll;Carroll & Khor;Wynder 1979:Dales et al 1983:Miller et al 1984:McKeown-Eyssen & Bright-See;Pickle et al 1988:Graham et al 1992:Thun et al 1993:Neugut et al;Zaridze et al;Little et al
Meat consumption	1980:Jain et al 1973:Haenszel et al 1975:Howell 1977:Knox 1979:Hirayama 1983:Manousos et al 1984:Pickle et al
Protein, Calories	1969:Gregor et al 1975:Armstrong & Doll;Carroll & Khor 1980:Jain et al 1986:Macquart-Moulin et al; Potter & McMichael;Thind 1987:Kune et al; Lyon et al 1990:Iscovich et al

Dietary Components	References
High intakes of sugar & fat	1985:Bristol et al
Monounsaturated fatty acids (needs confirmation)	1986:Macquart-Moulin et al
Oligosaccharides, not fat	1987:Tuyens et al
High intake of calories, total fat, & carbohydrates	1990:Freudenheim et al; Whittemore et al 1992:Iscovich et al
Frequent intake of refined starchy foods, eggs, fat-rich foods (cheese, meat)	1990:Negri et al 1992:Bidoli et al
High saturated fat, low fiber	1990:Whittemore et al 1992:Giovannucci et al 1993:Zaridze et al
High fiber, low fat	1978:Dales et al
Foods rich in fiber & other substances that may inhibit cancer	1975:Phillips;Modan et al 1978:Bjelke 1979:Dales et al
Total food fiber	1975:Modan et al 1977:Malhotra 1978:Bjelke; MacLennan et al 1979:Liu et al; McMichael et al 1980:Hunter et al; Reddy et al 1981:Rozen et al; Maisto & Bremner 1982:Helms et al; Jensen et al 1983:Jensen;Reddy et al 1984:McKeown-Eyssen & Bright-See;Powles & Williams; Nair et al 1985:Bingham et al; McKeown-Eyssen & Bright-See 1986:Macquart-Moulin et al 1987:Kune et al; Lyons et al 1992:Iscovich et al 1993:Neugut et al
Fiber-rich (esp. whole grain bread, pasta)	1990:Trock et al 1992:Howe et al 1992:Bidoli et al
Cereal fiber	1973:Irving & Drasar 1975:Armstrong & Doll; Howell 1977:Knox 1978:MacLennan et al 1982:Jensen et al 1984:Powles & Williams 1993:Little

Dietary Components	References
Vitamin A vegetables not high in fiber	1975:Phillips 1978:Bjelke 1986:Macquart-Moulin et al
Vegetables	1974:Bjelke 1975:Phillips;Howell 1977:Knox 1978:Graham et al 1980:Haenszel et al 1983:Jensen; Manousos et al 1986:Macquart-Moulin et al; Tuyns 1987:Kune et al 1991:Hu et al 1992:Bidoli et al
(chives & celery) (carrots & spinach)	
Grain versus vegetable fiber	1990:Freudenheim(a); 1993:Zaridze et al
Vegetable fiber, carotenoids, vitamin C	1990:Freudenheim(b) 1992:Thun et al
Legumes & folic acid	1991:Benito et al
High intake of total fiber, cereal fiber, calcium and phosphorus in relation to energy intake	1992:Arbman et al;Thun et al

Table 6.3 Diet and Colorectal Cancer References

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## DIET AND ESOPHAGEAL AND ORAL CANCER

There is some evidence that cancer of the mouth and throat is increasing. Most cases are attributed to the synergistic effect of a combined excessive use of tobacco products and alcohol. It has been estimated that drinkers who consume more than seven drinks (liquor, beer, wine) a week double their risk of mouth and throat cancers. However, poor nutrition in general (low intakes of vitamins A and B complex) has also been linked to an increase in these cancers.

Dietary factors that appear to be associated with the risk of esophageal cancer are low socioeconomic status; low intakes of riboflavin, vitamins C, and A; poor nutrition in combination with drinking alcohol and smoking cigarettes; high intakes of pickled or *moldy foods* possibly containing mycotoxins or N-nitroso compounds; excessive consumption of very hot beverages; and zinc and vitamin A deficiencies. Studies indicate that frequent consumption of fresh fruits and vegetables appears to be associated with a *lower risk for esophageal cancer*.<sup>1,2</sup>

TABLE 6.4 DIET AND ESOPHAGEAL AND ORAL CANCER REFERENCES

Dietary Components	References
Alcohol	1961:Wynder & Bross 1971:Schoenberg et al 1974:Breslow & Enstrom; Hakulinen et al 1977:Tuyens et al; Williams & Horm; Wynder & Stellman 1979:Chilvers et al; Tuyens et al 1980:Hinds et al; Lyon et al; Keller 1981:Pottern et al; van Rensburg; Schmidt & Popham
Alcohol and smoking cigarettes (oral cavity & larynx)	1962:Schwartz et al 1969:Martinez 1972:Rothman & Keller 1983:Tuyens 1991:LaVecchia et al 1993:Kabat et al
Low intakes of lentils, green vegetables, fresh fruit; animal protein; vitamins A & C, B <sub>2</sub> , nicotinic acid, calcium, magnesium, zinc, molybdenum	1974:de Jong et al 1975:Hormozdiari et al 1977:Iran-IARC Study Group; Foy & Mbaya 1979:Cook-Mozaffari
High intakes of pickles, pickled vegetables; moldy foods containing N-nitroso compounds	1981:van Rensburg; Mettlin et al 1982:Thurnham et al 1985:Zaridze et al 1992:Cheng et al
Nitrite-containing meats	1990:Gridley et al 1993:Hebert et al
Intake of very hot foods and beverages	1974:deJong et al

Dietary Components	References
Fresh fruit, cooked vegetables	1979:Cook-Mozaffari; Cook-Mozaffari et al 1981:Mettlin et
Fruit, fresh in particular	1990:LaVecchia et al 1991:LaVecchia et al 1993:Hebert et al
Vitamin A and B-carotene	1961:Wynder & Bross 1981:Mettlin et al
Milk, cheese, carrots, green vegetables & fruit	1991:LaVecchia et al
Vitamin C & A (laryngeal)	1981:Graham et al
Increased intake of fruits & vegetables, vitamin C, fiber, B-carotene & vitamin E	1990:Gridley et al
General "poor" nutrition (esophageal cancer) (laryngeal cancer)	1981:Ziegler et al 1990:LaVecchia et al

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## DIET AND FEMALE REPRODUCTIVE ORGAN CANCER

The evidence for an association between *endometrial cancer*, the third most common cancer among American women, and diet is indirect. Most women diagnosed with this cancer are 60 years of age or older. Some of the risks for this cancer are the same as for breast cancer: obesity, few or no children, early menarche, late age at menopause, and high socioeconomic status. The recent dramatic increase in the incidence of endometrial cancer has been clearly related to the use of exogenous estrogens at the time of menopause. Specific dietary factors do not appear to be related to this cancer.

*Ovarian cancer* causes more deaths than any other cancer of the female reproductive system. The risk of ovarian cancer decreases 1) if a women has one or more children, 2) for some birth control pill users, and 3) if no breast cancer is present. The evidence associating dietary factors, especially high fat diets, and ovarian cancer is largely indirect.

The effects of nutrition on risk of *cervical cancer* are not well founded; however, intake of foods high in retinol and carotene have been found to exert a protective effect against some squamous cell tumors most often responsible for this type of cancer. Other studies have shown that vitamin C and folacin are also associated with the decreased risk of cervical dysplasia.<sup>1,2</sup>

TABLE 6.5 DIET AND FEMALE REPRODUCTIVE ORGAN CANCER REFERENCES

Dietary Components	References
Endometrial Cancer	
• Obesity	1966:Wynder et al 1977:Elwood et al 1979:Lew & Garfinkel 1983:Henderson et al 1986:Jensen; LaVecchia et al
Ovarian Cancer	
• High intake of animal fat and low intake of vegetable fat	1983:Byers et al
• Coffee	1981:Trichopoulos et al 1984:LaVecchia et al
Fiber (not confirmed)	1986:LaVecchia et al

Table 6.5 Diet and Female Reproduction Organ Cancer References

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## DIET AND GALLBLADDER CANCER REFERENCES

In the United States, biliary tract (gallbladder and ducts) cancers are more common among American Indians than the general population. Incidence increases with age, especially over age 65. Cancers may develop in the gallbladder or in the duct cells. The risk of gallbladder cancer, more common among women, increases with the number of pregnancies. Cancer of the bile ducts tends to be more common among men than women; however, for American Indians, twice as many women have cancer of the bile ducts as do men. American Indians have a very high incidence of gallstones, which is a most major risk factor for gallbladder cancer and biliary tract cancer.<sup>1,2</sup>

Cancer at this site has been associated with obesity, type IV hyperlipoproteinemia<sup>2</sup> and both high-calorie and high-fat diets (Fraumeni JF Jr. Cancers of the pancreas and biliary tract: epidemiological consideration. *Cancer Res* 1975;35:3437-3446). However, the uniformly poor correlation of gallbladder cancer with high-fat diets negates a direct causal association. The evidence of a dietary etiology of this cancer is rather weak at this time, other than a possible association with obesity and an excessive intake of calories.<sup>2</sup>

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## DIET AND LIVER CANCER

Primary liver cancer develops first in the liver and then spreads to other organs. Persons with hepatitis B virus are at the greatest risk of developing liver cancer. Men develop this cancer more often than women. Persons who consume *large quantities of alcohol or excessive intakes of foods contaminated with aflatoxin* are at greater risk of developing liver cancer.<sup>1,2</sup>

TABLE 6.6 DIET AND LIVER CANCER REFERENCES

Dietary Components	References
Foods contaminated with aflatoxin	1968:Tung & Ling 1971:Alpert et al 1972:Shank et al (a,b) 1974:van Rensburg et al 1975:Wogan 1976:Peers et al 1980:Armstrong 1982:Bulatao-Jayme et al
Heavy alcohol consumption	1974:Hakulinen et al 1979:Jensen 1983:Yu et al 1984:Inaba et al

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## DIET AND LUNG CANCER

Tobacco use remains the number one cause of lung cancer for American men and women. Other causes include exposure to occupational carcinogens such as asbestos, radon, the inhalation of radon formed by disintegrating radium in uranium mines, high doses of ionizing radiation, mustard gas, chloromethyl ethers, chromium, nickel, and inorganic arsenic.

There is now a growing body of evidence to show that low intakes of vitamin A food sources and/or vitamin A precursors (e.g., carotene) are associated with increased risk of lung cancer, *especially among heavy smokers*. Because the indices of vitamin A intake in these studies were derived from foods *that also contain other substances that prevent or have the ability to produce cancer*, it is also possible that dietary constituents other than preformed vitamin A or carotene are relevant in lowering cancer risks. It is important to note that this is one reason why nutritionists promote the consumption of foods as sources of nutrients rather than vitamin or mineral supplements.<sup>1,2</sup>

TABLE 6.7 DIET AND LUNG CANCER REFERENCES

Dietary Components	References
Dietary fat, cholesterol	1983:Hinds et al (a,b) 1987:Byers et al; Wynder et al
Smoking and poor nutrient intake	1993:Chyou et al
Vitamin A rich foods	1975:Bjelke 1979:Mettlin et al 1980:Gregor et al 1983:Kvale et al
Frequent consumption of green or yellow vegetable sources of B-carotene	1977:MacLennan et al 1979:Hirayama 1985:Nomura et al 1986:Menkes et al
B-carotene	1981:Shekelle et al 1984:Hinds et al; Ziegler et al 1985:Samet et al 1987:Byers et al 1991:Shekelle et al 1992:Shibata et al
Studies showing the association with serum retinol is not confirmed	1980:Wald et al 1981:Kark et al 1983:Hinds et al 1984:Peleg et al 1985:Salonen et al 1986:Friedman et al; Menkes et al; Wald et al

Dietary Components	References
Increased vegetable intake	1990:Jain et al 1992:Forman et al 1993:Steinmetz et al
High intake of carotene-containing fruits & vegetables	1990:Fontham; Willet 1991:Harris et al
Antioxidants:carotenoids, vitamins E & C	1991:Knekt et al 1993:Knekt
Increased fruit intake	1991:Fraser et al 1992:Forman et al 1993:Steinmetz et al

Table 6.7 Diet and Lung Cancer References

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## DIET AND PANCREATIC CANCER

Pancreatic cancer is a "silent" disease. Very little is known about what causes or prevents it. This organ has two major functions, 1) it sends insulin into the bloodstream to control the amount of sugar in the blood, and 2) sends pancreatic juice into the intestine to aid in digesting food. Cancer tends to develop in the cells of the small tubes or ducts that transport the pancreatic juice. *American Indians are a high risk group for this fatal disease. This cancer has been linked to heavy smokers and persons with diabetes mellitus.*

International studies conducted prior to 1980 (Armstrong and Doll, 1975; Lea, 1967; Stocks, 1970; Wynder et al., 1973) investigated the association between income and intake of several foods with the incidence and mortality rates of pancreatic cancer. The findings suggested a direct association between mortality and the consumption of fats and oils, sugar, animal protein, eggs, milk, and coffee. However, there is *limited evidence* that these foods cause or increase the risk for pancreatic cancer.<sup>1,2</sup>

TABLE 6.8 DIET AND PANCREATIC CANCER REFERENCES

Dietary Components	References
Meat consumption	1968:Ishii et al 1986:Mack et al
Alcohol consumption	1968:Burch & Ansari 1978:Blot et al; Cubilla & Fitzgerald 1992:Bueno de Mesquita et al
Carbohydrates	1990:Thouez et al

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## DIET AND PROSTATE CANCER

Cancer of the prostate is a common cancer among American men and its incidence increases with age, especially over 65 years. Studies of migrating populations suggest that diet and life-style play important roles in the risk of developing this cancer. Prostate growth and function depends on testosterone, the production of which may be affected by diet. The incidence of prostate cancer is correlated with other cancers associated with diet, e.g., breast, colon and rectal cancers. The direct cause of prostate cancer remains unclear, but there is now evidence that *high intakes of fat and animal protein foods increase the risk of prostate cancer*. There is some evidence that foods rich in vitamin A or its precursors and vegetarian diets are associated with a lower risk.<sup>1,2</sup>

TABLE 6.9 DIET AND PROSTATE CANCER REFERENCES

Dietary Components	References
Total fat intake	1974:Howell 1975:Armstrong and Doll 1978:Blair & Fraumeni
Intake of high fat foods	1977:Rotkin 1978:Blair & Fraumeni 1983:Graham et al 1984:Snowdon et al 1985:Heshmat et al 1988:Kolonel et al
Overweight or obesity	1979:Lew & Garfinkel 1984:Snowdon et al 1986:Talamini et al 1988:Kolonel et al
Vitamin A as a possible risk factor (needs confirmation)	1983:Graham et al 1985:Heshmat et al 1987:Kolonel et al 1990:Reichman et al
Carotenes (not retinols)	1987:Kolonel et al
Intake of some vegetable sources of carotenes	1982:Schuman et al 1983:Ross et al
Retinols, carotenes, coffee, alcohol	1990:Hsing et al
Consumption of yellow-orange fruits & vegetables, dark green & cruciferous vegetables, tomatoes; beta-carotene, lycopene, lutein, indoles, phenols or other phytochemicals	1991:LeMarchand et al

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## DIET AND STOMACH AND GASTROINTESTINAL CANCER

Between 1951 and 1978, death rates of Americans from stomach cancer decreased drastically; however, this cancer still remains a problem. Studies of immigrants to the United States suggest that gastric cancer is related, in part, to dietary factors established early in life. The factors increasing risk may include frequent consumption of *smoked food* (which in some parts of the world leads to increased exposure to polycyclic aromatic hydrocarbons) and frequent ingestion of *salt-pickled foods or foods containing nitrate and nitrite* (which may result in subsequent *in vivo* production of nitrosamines) and other carcinogens produced in food by preservation treatments and cooking. Low socioeconomic status, cigarette smoking, heredity, and exposure to radiation are also factors that increase the risk for this cancer.

*Nitrosamines* are potent carcinogens that form in the stomach. When nitrates, found in some water supplies, some green vegetables, cured meats, and cheeses, combine with bacteria in the mouth, nitrites form. These nitrites combine with some food components, drugs, or other substances to form carcinogenic nitrosamines. Studies have shown that *vitamin C tends to be a natural defense* against nitrosamines by preventing their formation. *Consumption of fresh fruits and vegetables rich in vitamin C* have been found to be protective and reduce the risk of stomach cancer.<sup>1,2</sup>

TABLE 6.10 DIET AND STOMACH CANCER REFERENCES

Dietary Components	References
Limited vitamin C intake	1964:Meinsma
Dried or salted fish; smoked fish & other smoked foods; pickled vegetables & other pickled foods	1966:Dungal 1971:Imai et al 1976:Haenszel et al 1985:Risch et al 1987:Joossens & Geboers
High concentrates of salt or nitrates & nitrites in foods or drinking water	1973:Hill et al 1975:Armijo & Coulson 1976:Correa et al 1977:Zaldivar 1979:Tannenbaum et al 1986:Takahashi
Increased intake of nitrites & protein Increased intake of processed meats; fish & nitrites- not nitrates; high salt intake	1990:Buiatti et al 1991:Boeing (a); Gonzalez et al
Increased intake of sodium, total fat & retinol food sources	1990:Graham et al
Increased intake of sausage, table salt, frequency of eating hot meals, irregular eating pattern	1991:Boeing et al (b)

Dietary Components	References
Increased intake of refined carbohydrates Low consumption of fruit	1990:Thouez 1991:Yu & Hsieh
Tobacco, alcohol, and poor nutrient intake	1990:Nomura et al 1993:Kabat et al
Fresh fruits and vegetables rich in vitamin C (in particular, tomatoes, carrots, coleslaw & red cabbage)	1966:Higginson 1972:Graham et al 1975:Haenszel & Correa 1978:Bjelke 1981:Kolonel et al 1985:Risch et al;Correa et al
Fresh fruit & vegetables rich in C; olive oil	1990:Buiatti et al 1990:Chyou et al 1991:Boeing; Boeing & Frentzel-Beyme
Ability of vitamin C to inhibit the formation of carcinogenic N-nitroso compounds	1972:Mirvish et al 1990:Buiatti et al 1991:Boeing
Increased intake of Allium vegetables (garlic & onions)	1989:You et al
B-carotene in raw vegetables Celery, cucumbers, carrots, green peppers, tomatoes & onions	1972:Graham et al; Haenszel et al 1990:Graham et al 1991:Boeing
Ample cheese, non-white breads, vegetables & fruits (radishes & onions, in particular); and fruit consumption between meals	1991:Boeing et al

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## CHAPTER 7. DIETARY RECOMMENDATIONS FOR HEALTH AND THE CONSUMPTION PRACTICES OF NATIVE AMERICANS

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### CHAPTER OBJECTIVES:

- PROVIDE THE DIETARY RECOMMENDATIONS OF THREE NATIONALLY RECOGNIZED AUTHORITIES ON HEALTH AND NUTRITION.
  - PROVIDE BACKGROUND INFORMATION ON THE TRADITIONAL CONSUMPTION PRACTICES OF NATIVE AMERICANS.
  - PRESENT FACTORS THAT HAVE IMPACTED ON THE HEALTH AND NUTRITIONAL STATUS OF NATIVE AMERICANS.
  - PRESENT THE CONTEMPORARY NUTRITION-RELATED HEALTH CONCERNS OF NATIVE AMERICANS.
  - PROVIDE WHAT IS KNOWN ABOUT THE CONTEMPORARY CONSUMPTION PRACTICES OF NATIVE AMERICANS AND COMPARE THESE PRACTICES WITH THE DIETARY RECOMMENDATIONS.
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### DIETARY RECOMMENDATIONS FOR HEALTH

Over the last two decades, most U.S. scientific organizations and government agencies have agreed that certain eating practices increase or reduce the risk of chronic diseases,<sup>1</sup> and that Americans need dietary guidance to promote good health and prevent chronic diseases.<sup>2</sup> Table 7.1 presents a comparison of the most recent dietary guidelines from health and nutrition experts at the National Cancer Institute (1988,1992)<sup>3-5</sup>, the National Academy of Sciences (1989)<sup>2</sup>, and the U.S. Departments of Agriculture (USDA) and Health and Human Services (DHHS)(1990).<sup>6</sup> What do these guidelines mean to the average lay-person and how can the information be of assistance to the consumer when purchasing foods or preparing meals? The following explanations are provided by each organization.

#### The Dietary Guidelines of the National Cancer Institute

In 1986, *the National Cancer Institute* (NCI) established a set of quantified objectives to reduce significantly the annual cancer mortality rate by the year 2000. Their 1988 diet and cancer messages were based on evidence from a variety of epidemiologic and animal studies and promoted the positive attributes of eating a low-fat, high-fiber diet rather than over-emphasizing the fact that people should control their weight. The NCI Dietary Guidelines<sup>4</sup>

**Table 7.1 A Consensus of Dietary Recommendations Among Health Organizations, 1988-90**

	National Cancer Institute, 1988/92 <sup>1/2</sup>	National Academy of Science, 1989 <sup>3</sup>	USDA/DHHS (1990) <sup>4</sup>
FAT	Reduce fat intake to 30% or less of calories	Reduce total fat intake to 30% or less of calories; saturated fat to less than 10% of calories; cholesterol to 300 mg per day	Choose a diet low in fat (30% or less of calories), saturated fat (10% or less of calories) & cholesterol
CARBOHYDRATES/ FIBER	Increase fiber intake to 20-30 grams daily with an upper limit of 35 grams	Carbohydrates should total more than 55% of calories	NO SPECIFIC GUIDELINE
FRUITS/ VEGETABLES GRAINS	Include a variety of vegetables & fruits in the daily diet (1992: Eat 5 fruits and vegetables daily)	Daily, eat 5 or more 1/2 cup servings of fruit & vegetables; Increase starch & complex carbohydrate intake by eating 6 or more servings of breads, cereals, grains	Choose a diet with plenty of vegetables, fruits & grains products
SUGAR	NO SPECIFIC GUIDELINE	NO SPECIFIC GUIDELINE	Use sugars only in moderation
SALT/ SODIUM	Minimize consumption of salt-cured, salt-pickled, & smoked foods	Limit salt consumption to 6 grams per day	Use salt & sodium only in moderation
ALCOHOL	Consume alcoholic beverages in moderation, if at all	Does not recommend alcoholic beverage, but if consumed, no more than 1 oz of ethanol daily	If you drink alcoholic beverages, do so in moderation
OBESITY	AVOID IT	Balance food intake and physical activity to maintain appropriate body weight	Maintain healthy weight

<sup>1</sup> Diet, Nutrition & Cancer Prevention: The Good News. US DHHS, PHS, NIH Pub. No. 87-2878. Bethesda, MD, 1986.

<sup>2</sup> Eat More Fruits & Vegetables: 5-A-Day for Better Health. US DHHS, PHS, NIH Pub. No. 92-3248. Bethesda, MD, 1992.

<sup>3</sup> National Research Council (U.S.) Committee on Diet and Health. Diet and Health: Implications for Reducing Chronic Disease Risk. Committee on Diet and Health, Food and Nutrition Board, Commission on Life Sciences, National Research Council, National Academy of Sciences: Author. 1989.

<sup>4</sup> Nutrition and Your Health: Dietary Guidelines for Americans, U.S. Departments of Agriculture and Health and Human Services. Washington, DC: Government Printing Office. 1990.



encourage people to:

- 1 ***Reduce fat intake to 30% or less of calories.*** A diet low in total fat may reduce the risk for cancers of the breast, prostate, colon, and rectum. Such a diet will probably be low in saturated fat and cholesterol and may also reduce the risk of heart disease.
- 2 ***Increase fiber intake to 20-30 grams per day, with an upper limit of 35 grams.*** Most individuals eat a diet low in starch and fiber. Health experts recommend individuals increase the amounts of fiber in the daily diet by eating fruits, vegetables, potatoes, whole grain breads and cereals, and dry peas and beans.

Although fibrous foods play an important role in reducing the risk of colon and rectal cancers, it is not known if the type of fiber or the substances in fibrous foods are acting as protective agents. Therefore, it is important to eat a variety of fibrous foods. Different types of fiber function differently in the body. For example, *soluble dietary fibers* such as bran, pectin, and guar gum stimulate fecal excretion of bile acids and lower serum cholesterol. *Insoluble dietary fibers*, such as cellulose and hemicellulose (whole grain cereals and bread products), decrease intestinal transit time and increase stool weight and volume. At present, knowledge about the fiber composition of foods is limited; however, the foods recommended by the NCI are known to have a high concentration of fiber.<sup>2</sup>

It is also important not to exceed the recommended fiber intake since studies have shown that fibers containing phytates, saponins, and other compounds may interfere with micronutrient utilization and absorption of calcium, magnesium, zinc, and phosphorus.<sup>7</sup>

- 3 ***Include a variety of vegetables and fruits in the daily diet*** because no one food provides all the nutrients that a person needs.

In 1988, an evaluation of national survey data showed that most Americans ate minimal servings of fruits and vegetables foods daily.<sup>8</sup> Since then, several studies have shown that fruit and vegetable consumption helps to reduce the risk of some cancers (Chapter 6), heart disease, and diabetes. Based on this evidence, the NCI quantified their original vegetable and fruit message and launched the *5-A-Day for Better Health Program*<sup>5</sup> in 1992. The program was designed to increase the consumer's awareness of the importance of eating fruits and vegetables and to provide consumers with specific information on how to translate the 5-A-Day recommendations (Table 7.2) into a daily practice. The program encourages Americans to meet the recommendation via promotions in a variety of community settings such as worksites, health departments, supermarkets.

Emphasized is the daily consumption of at least one serving of a *vitamin A-rich food, a vitamin C-rich food, a high-fiber food; and cruciferous vegetables* several times a week. One serving is equal to:

- . 1/2 cup of fruit

- . 3/4 cup of juice
- . 1/2 cup of cooked vegetable
- . 1 1/2 cup of raw leafy vegetables, or
- . 1/4 cup of dried fruit

Foods with a high level of *vitamins A and C*, and a precursor of vitamin A called beta-carotene, may reduce the risk of certain cancers. Such foods include dark green leafy vegetables, other green vegetables; the red, yellow, and orange vegetables and fruits; and citrus fruits and juices (Table 7.2). A person who seldom or never eats these foods is at a greater risk of developing cancer than persons who eat these foods daily or weekly.

*Dietary fiber* comes from plant cells. Some types of fiber are partially digested by man; other types are not digested at all. Fiber helps to move other foods eaten through the intestines and out of the body, promoting a healthy digestive tract. NCI recommends the consumption of natural foods rich in fiber rather than fiber supplements.

*Cruciferous vegetables* (foods from the cabbage family) are good sources of vitamins, minerals, and fiber, and may reduce a person's cancer risk. These foods include bok choy, broccoli, brussels sprouts, cabbage, cauliflower, kale, kohlrabi, mustard greens, rutabagas, and turnips and their greens. Eating a variety of these vitamin-rich foods, rather than relying on supplements, will help to protect an individual from cancer.

- 4 *Avoid obesity.* Obesity is a risk factor for many diseases, including heart disease, high blood pressure, diabetes, and some cancers. The NCI encourages individuals to exercise daily, maintain desirable weight, and get regular physical checkups.
- 5 *Consume alcoholic beverages in moderation, if at all.* Drinking too much alcohol can lead to many health problems. Heavy drinking is associated with cancers of the mouth, throat, esophagus, and liver. Cancer risk is especially high for heavy drinkers who smoke. Alcoholic drinks are also high in calories and low in vitamins and minerals.
- 6 *Minimize consumption of salt-cured, salt-pickled, and smoked foods.* Too much sodium in the diet may contribute to high blood pressure, especially for people with a family history of high blood pressure. Untreated high blood pressure can lead to heart attacks, strokes, and kidney disease.

### The Dietary Guidelines of the National Academy of Sciences

The 1989 Dietary Guidelines of the National Academy of Sciences is discussed in-depth in their report, *Diet and Health: Implications for Reducing Chronic Disease Risk*.<sup>2</sup> The following is a brief overview of what the Report suggests is a beneficial diet to promote good health among American adults and children, and how this translates into daily practice. Also

provided is the rationale for each recommendation. These recommendations encourage people to:

- *reduce total fat intake to 30% or less of calories; reduce saturated fatty acid intake to less than 10% of calories and the intake of cholesterol to less than 300 mg daily.*

**Rationale:** This recommendation is based on the evidence linking saturated fatty acids and dietary cholesterol to coronary heart disease; the evidence linking high-fat diets to cancer has been less persuasive. However the weight of evidence indicates that high-fat diets are associated with a higher risk of several cancers, especially of the colon, prostate, and breast. It is suggested that individuals:

- . substitute fish, poultry without skin, lean meats, and low- or nonfat dairy products for fatty meats and whole-milk dairy products.
  - . eat more vegetables, fruits, cereals, and legumes; and limit the intake of oils, fats, egg yolks, and fried and other fatty foods.
  - . limit the intake of baked goods containing high levels of fat.
  - . limit the intake of spreads (butter, margarine) and salad dressings.
  - . limit the intake of cholesterol-raising foods such as dairy and meat products, egg yolks, shellfish, organ meats, and some oils- coconut, palm, and palm-kernel-oils.
- *eat five or more servings of a combination of vegetables and fruits daily, especially green and yellow vegetables and citrus fruits. Also, increase the intake of starches and other complex carbohydrates by eating six or more daily servings of a combination of bread, cereals, and legumes.*

**Rationale:** This recommendation is based on international studies that have shown that people who habitually eat more plant foods have lower risk factors for atherosclerotic cardiovascular diseases. While the mechanism for linking the frequent consumption of fruits, vegetables, especially green and yellow vegetables and citrus fruits with decreased susceptibility to cancers of the lung, stomach, and large intestine is unclear, there is strong evidence that a low intake of carotenoids (present in green and yellow vegetables) contributes to an increased risk of lung cancer. The Report also recommends the intake of natural foods rather than fiber supplements.

Table 7.2 The National Cancer Institute's 5-A-DAY Guidelines

FOOD	SERV	VITAMINS A C	FIBER	COOKED FOOD UNLESS SPECIFIED	SERV	VITAMINS A C	FIBER	CRUCIFEROUS VEGETABLES
<b>FRUITS</b>								
Apple	1		X	Asparagus	1/2 C		X	
Apricots	3	O	X	Beans, green	"		X	
Banana	1		X	Bok choy	"	O	X	Yes
Figs	2		O	Broccoli	"	X	X	Yes
Grapes	1 C		X	Brussels sprouts	"		X	Yes
Grapefruit	1/2		X	Cabbage	"		X	Yes
Kiwi Fruit	1	O	X	Carrots	"	O	X	Yes
Nectarine	1		X	Cauliflower	"		X	
Orange	1	O	X	Chili peppers	1/4 C	O	X	Yes
Peach	1		X	Corn	1/2 C		X	
Pear	1		O	Dried peas/beans	"		O	
Plums	2		X	Eggplant	"		X	
Prunes	4		O	Green pepper	"		O	
				Greens:beet/chard	"	O	X	Yes
	1/2 C			mustard/kale/turnip;	"			
Cantaloupe	"	O	X	dandelion	"			
Honeydew	"	X		Lettuce, raw	1 C			
Papaya	"	X		Spinach	"	O	X	
Pineapple	"		X	Romaine	"	X		
Raisins,	1/4 C		X	red or green garden	"	X		
Raspberries	"	X	X	iceberg	"			
Strawberries	"	O	X	Okra-cooked	1/2 C	X		
Watermelon	1 C	X		Peas, green	"		X	
				Potato, white, baked	1 med.	X		
JUICE	3/4 C			Spinach, cooked	1/2 C	O	X	
Orange	"	O		Squash, winter	"	O	X	
Grapefruit	"	O		Sweet Potato	"	O	X	
Tomato	"	O		Tomatoes, raw	1	X	X	
				Zucchini, cooked	1/2 C		X	

Source: Eat More Fruits & Vegetables: 5-A-Day for Better Health. US DHHS. PHS. NIH Pub. No. 92-3248; C = cup  
 x = These foods supply at least 25% of the U.S. RDA for vitamins A or C or at least 1-3 grams of dietary fiber per serving  
 o = These foods supply at least 50% of the U.S. RDA for vitamins A or C or at least 4 grams of dietary fiber per serving.

- *balance food intake and physical activity to maintain appropriate body weight.*

**Rationale:** This recommendation was prompted by the fact that excess weight is associated with increased risk of several chronic diseases, including hypertension, coronary heart disease, gallbladder disease, and endometrial cancer, and that the body weight and body mass index (BMI) of Americans is increasing. The Report suggests that all healthy people maintain physical activity at a moderate level, improve physical fitness, and moderate their food intake to maintain appropriate body weight. It is suggested that overweight people increase their physical activity and reduce their caloric intake, and those with a family history of obesity should avoid high calorie foods.

- *not to drink alcoholic beverages.* The committee who developed these guidelines "does not recommend alcohol consumption." However, they did not recommend alcohol avoidance, except for pregnant women. For persons who drink, it is suggested that no more than one ounce of pure alcohol be consumed daily (one ounce equals two cans of beer, two small glasses of wine, or a one ounce shot glass of liquor).

**Rationale:** Excessive alcohol intake increases the risk of heart disease, high blood pressure, chronic liver disease, some forms of cancer, neurological diseases, nutritional deficiencies, and other disorders. Pregnant women or women attempting to conceive should not drink alcohol because of the risk of damage to the fetus.

- *limit the total daily intake of salt (sodium chloride) to 6 grams or less. Limit the use of salt in cooking or at the table. Salty, highly processed salty, salt-preserved, and salt-pickled foods should be consumed sparingly.*

**Rationale:** This recommendation is based on international studies showing that habitual daily consumption of salt (6 grams) is associated with elevated blood pressure. This recommendation applies more to individuals who are most susceptible to developing salt-induced hypertension. The evidence linking salt intake with stomach cancer is less persuasive than for the link with hypertension. However, the frequent consumption of salt-preserved or salt-pickled foods has been shown to increase the risk of stomach cancer.

The *Diet and Health Report* also promotes 1) the intake of low- or nonfat dairy products and dark-green vegetables for adequate calcium, an essential nutrient needed by most young children and adolescents for growth and development, and by most women, 2) not taking more than one vitamin-mineral supplement daily because an excessive intake has no known health benefit but may be harmful to health, and 3) maintaining an optimal intake of fluoridated water to reduce the risk of dental caries. If the region has no fluoridated water, the Report supports the use of dietary fluoride supplements in the amounts recommended by the dentist in the community.

## The 1990 Dietary Guidelines for Americans

In 1990, the U.S. Department of Agriculture (USDA) and the U.S. Department of Health and Human Services (DHHS) jointly published seven guidelines for a healthful diet which are considered the best, most current advice from nutrition experts. These recommendations are known as the *1990 Dietary Guidelines for Americans*<sup>6</sup> and are appropriate for persons ages 2 years and over. These Guidelines were developed because national surveys has shown that many Americans select foods that provide too many calories, and too much fat (especially saturated fat), cholesterol, and sodium, but not enough complex carbohydrate, fiber, vitamins and minerals. The consistent consumption of such a diet contributes to obesity, heart disease, high blood pressure, stroke, diabetes, and some forms of cancer. The dietary rationale for the following recommendations are similar to those of the two previous health organizations. These Guidelines encourage people to:

- . Eat a Variety of Foods
- . Maintain Healthy Weight
- . Choose a Diet Low in Fat, Saturated Fat and Cholesterol
- . Choose a Diet with Plenty of Vegetables, Fruits and Grain Products
- . Use Sugars Only in Moderation
- . Use Salt and Sodium Only in Moderation
- . If You Drink Alcoholic Beverages, Do So in Moderation

Details of each recommendation will be provided later in this chapter when discussing whether or not it is feasible for Native Americans to meet the *1990 Dietary Guidelines*.

A fourth major health report, *The Surgeon General's Report on Nutrition and Health*<sup>9</sup>, is not detailed here because it strongly supports the Federal nutrition policies as stated in the *Dietary Guidelines for Americans*. The *Surgeon General's Report* also recommends that 1) communities fluoridate their water at optimal levels to prevent tooth decay; 2) that children and adolescents restrict their intake of refined sugars to prevent dental caries, and 3) that adolescent girls and adult women should increase their consumption of calcium-rich foods for growth and development, and iron-rich foods to prevent iron deficiency anemia. The Report also suggested that persons at high risk for diet-related cancers because of family history, obesity, or excessive alcohol intake should receive counseling from qualified health professionals.

Before evaluating whether or not Native Americans have adhered to any of these recommendations, it is important to understand what the traditional consumption practices of this culture were before the incidence and mortality rates for cancer and other chronic diseases began to rise. It is equally important to understand what changes occurred over time that have promoted their contemporary consumption practices and high rates of obesity and diabetes. This next part presents an overview of what is known about the traditional consumption practices of Native Americans prior to European influence.

## CONSUMPTION PRACTICES OF NATIVE AMERICANS

### Traditional Consumption Practices

Prior to European influence, the traditional diet of most Northern American Indian tribes included a variety of foods they gathered, hunted, or caught during each season of the year. At that time, there were seven distinct Native American groups: the woodsmen of the eastern forests, the hunters of the plains, the Navajo shepherds, the Pueblo farmers, the desert dwellers, the northern fishermen, and the seed gatherers.<sup>10</sup> When food was abundant, native people ate large quantities for satiety, the excess of which was stored as body fat; however, their active life-style (hunting, fishing, food gathering, festive and ceremonial activities) kept their bodies lean. Their traditional consumption pattern consisted of one meal eaten in late morning; the food was cooked and eaten out of a single pot, most often with their fingers or bread. During the remainder of the day, stews were kept simmering over a fire, and dried foods were eaten as snacks. As a means of hospitality, anyone could eat from the food pot. Feasting was an essential part of most ceremonies to ensure the success of the harvest.<sup>11</sup>

Traditional food preparation methods included boiling or roasting game meats over an open fire of moderate heat for long periods of time, sun drying, or steaming foods wrapped in wet leaves that were placed in underground pits. Meats and fish were generally dried or smoked. People of the northwest coastal areas usually hung their fish filets in the smoky rafters above the central fires of longhouses or used their rooftops in sunny weather. Alaska Natives had less trouble storing their meats during cold weather than did the American Indians; they refrigerated their meats in pits dug in the frozen ground.<sup>11</sup>

Generally, Native Americans ate seeds and nuts raw or toasted, or ground into a meal used to thicken stews, or added to breads. Mashed berries were dried into large sheets or used as a paste with dried meat and fat (pemmican).<sup>12-14</sup> Most of the vegetable foods were eaten fresh or dried. Corn (1300 B.C.), kidney beans (100 B.C.-100 A.D.), and squash (900 A.D.) appeared the earliest in the food chain,<sup>15</sup> and were seasoned with ashes, salt, some chile peppers, or spicy berries.<sup>12-14</sup>

Native Americans living in the eastern woodlands ate a variety of nuts, berries, seeds, and roots. Along the coast, there was an abundance of lobsters, clams, and mussels. Lobster was often used as bait to catch bass or cod. Deer and turkeys were plentiful. In the midwest and northeast, sunflower seeds and roots (4000-1000 B.C.), and Jerusalem artichokes abounded. Other domesticated plants included marsh elder, maygrass, knotweed, and goosefoot. The latter two plants were rich sources of oil and protein.<sup>16</sup> Squash, corn, and beans were often consumed.

Native people of the Great Lakes region followed the food chain, often making nuts, berries, and wild rice part of their daily intake. Wild rice was their single most nutritious food and was popped like corn, used as meal in making bread, or boiled in water in birch bark containers over slow fires.<sup>17</sup> In woodland areas, maple sap was another important food item that was boiled into a syrup and often granulated.<sup>18</sup>

Each spring on the northeast coast, the Delaware Indians gathered the first shoots of dandelions, milkweed, poke, lamb's-quarters, mustard, dock, and watercress and parboiled them cooked them with meat. Fiddlehead fern fronds were a popular green among New England natives.<sup>19</sup> Among southeast natives, corn and beans were staples. Corn, boiled in wood ash, swelled into hominy. When dried and ground, it was the basic ingredient for bread; fresh off the cob, it was combined with beans and venison to make stews.<sup>20</sup>

With agricultural development came a change in health status.<sup>21</sup> Hunter-gatherers came to depend on a few crops, which were supplemented by hunting and gathering. Agriculture provided a stable food base but at the expense of hunting sources of better quality protein (meat, fish).<sup>22</sup>

Although there were similar consumption practices among most Native Americans, major differences in consumption were due, in part, to availability and the role foods played in tribal spiritual and harvest ceremonies. Tables 7.3-7.8 show the traditional foods consumed by different tribes of American Indians and Alaska Natives prior to the arrival and influence of the Europeans.<sup>23-26</sup> These tables do not include all there is to know about their food consumption. Discussions with tribal elders and investigations of other available historical documents are needed to complete these tables.



Table 7.3 TRADITIONAL FOODS OF SOUTHEAST AND NORTHEAST AMERICAN INDIANS<sup>1</sup>

		SOUTHEAST: Choctaw, Chickasaw, Creek, Seminole Cherokee, Natchez, Micosuke	NORTHEAST: Iroquois-Mohawk, Onondaga, Cayuga, Oneida, Seneca; Algonquians- Abnaki, Penobscot, Passa- Maquoddy, Malecite Delaware, Chippewa, Potawamani, Ottawa)
FOOD GROUPS			
FRUITS & FLOWERS		Huckleberries, blackberries, service berries, strawberries, wild opossum grapes, summer grapes, dried berries & fruit	Cranberries, spicebush berries
VEGETABLES & HERBS		Dried whole green beans, wild onions, corn, tomatoes, tomato pones, corn pones, carrots, sweet potatoes, sassafras tea	Dandelions, poke, lamb's quarters, mustard greens, dock, wild watercress, sunchokes, succotash
LEGUMES/NUTS & SEEDS		Beans: navy, peabeans, black-eyed, yellow-eyed, pinto, limas, & black; bean cakes; hominy: stewed, fried, baked in pudding, traditional drinks, hash; nuts: acorns, peanuts, nutmeats; seeds	Sunflower seeds, beans: navy, kidney, baby limas, pinto, black
FOUR LEGGED		Deer, gar	Deer
FINNED & SEAFOOD		Crabs, bass, squid	Lobster, clams, mussels, bass, cod, codfish balls, maple-basted broiled bluefish, maple sugar smoked fish
WINGED		Wild geese, eggs	Turkey (honey-based & roasted)
GRAINS/FLOURS		Cornmeal, crackling cornbread	Wild rice, johnny cakes
SWEETS		Honey, broomcorn (sorghum molasses)	Maple syrup, cranberry maple sauce, hazelnut cakes
FATS		(1800s): Salt pork & bacon replaced bear grease	

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003, 1991.

Table 7.4 TRADITIONAL FOODS SPECIFIC TO SOUTHEASTERN AND NORTHEASTERN AMERICAN INDIAN TRIBES<sup>1</sup>

TRIBES	COMMONLY CONSUMED FOODS
<b>ALGONQUIANS:</b>	Cider-basted roast goose, maple-sugar candy, acorns, butternuts, hickory nuts, walnuts, grapes, chenopod seeds, Canada plums, hazelnuts, thornapples, plums, bearberries, blackberries, blueberries, elderberries, beechnuts, sumac berries, pepperoot; haddock, trout, bass, wild mushrooms- morels, crimini, shitake; cornmeal cakes, maple popcorn balls
<b>CATAWBA:</b>	Potatoes, beans, squash, corn
<b>CHEROKEE:</b>	Venison, Jerusalem artichokes (sunchokes), pecans, apples; squirrel, rabbit or turkey w/corn, beans & tomatoes; apples, honey, huckleberries
<b>CHIPPEWA:</b>	Wild rice, maple syrup; duck stuffed w/wild rice and wild mushrooms
<b>CHOCTAW:</b>	Hickory nuts, hominy w/salt pork, acorn, File (powder made from sassafras leaves that is used to thicken gumbo, American persimmon
<b>CREEK:</b>	Green corn, blackberries
<b>HOUMA:</b>	Gumbos w/File
<b>IROQUOIS:</b>	Green corn, beans, squash, wild strawberries & wild strawberry bread
<b>ONEIDA:</b>	Sauteed morels
<b>NATCHEZ:</b>	Corn, pumpkins, squash, melons
<b>PENOBSCOT &amp; NARRAGANSETT:</b>	Clambake: clams, lobster, oysters, mackerel, bluefish, mussels, potato, corn in husks, sausages wrapped in cornmeal
<b>SEMINOLE:</b>	Pompano, oranges, grapes
<b>SHAWNEE:</b>	Squaw cakes, wild grapes, spiceberries, pecans, walnuts

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003. 1991.

Table 7.5 TRADITIONAL FOODS OF THE GREAT PLAINS AND SOUTHWESTERN AMERICAN INDIANS<sup>1</sup>

		GREAT PLAINS: NORTHERN: Sarai, Blackfoot, Plains Ojibway, Plains Cree, Assiniboin; CENTRAL: Gros Ventre Crow, Wind River Shoshone, Mandan, Hidatsa, Arikara, Teton Lakota, Yanktonai Dakota, Santee Dakota, Sioux, Cheyenne, Omaha, Pawnee, Arapahoe, Oto, Iowa; SOUTHERN: Kansas, Missouri, Osage; Apache (Jicarilla, Kiowa, Mescalero, San Carlos, White Mountain, Chiricahua, Lipan), Kiowa, Quapaw, Comanche, Wichita, Ute	SOUTHWEST: Pueblo, Navajo, Pima, Papago, Tohono O'odam; RIO GRANDE PUEBLOS: Taos, Taos, Santa Clara, San Ildefonso, San Juan, Santa Domingo, Cochiti; Picuris, Jemez, Zia, Isleta, Nambé, Tesuque, San Santa Ana, Sandia, Felipe, Pojoaque; WESTERN PUEBLOS: Zuni, Hopi, Acoma, Laguna
FOOD GROUPS			
FRUITS & FLOWERS		Choke cherries, service berries, buffalo berries, wild plums, sand cherries, yellow & black currants, wild raspberries, wild strawberries, rose hips, prickly pear, cactus buds, calamus and cedar berries	Pumpkins, cantaloupe, water- & muskmelons, peaches, cactus: prickly pear, barrel, cholla & saguaro, cactus relish, yucca fruit, apricots, juniper berries
VEGETABLES & HERBS		Corn, squash, sunflowers, wild turnips, wild arrowroot, cattail bulbs, wild onions, wild potatoes, lamb's quarters, nettle leaves, young cattail stalk cores, "tree ears", (wild mushrooms); wild mint tea, inner bark of elm trees, choke cherry trees, roots of wild rose bushes, wild sage	Corn-7 colors, hominy, wild carrots, roots, wild onions, garlic, squash & pumpkin blossoms, succotash, chili peppers, chili pequin, (wild small hot chili), coriander
LEGUMES		Beans	Beans: tepary or Anasazi, chick peas pumpkin seeds, pinon nuts
FOUR LEGGED		Buffalo, buffalo-sage sausages, Pemmican (dehydrated meat or fruit), meat:lungs, liver, kidney, spleen, intestine, buffalo jerky, venison mincemeat pie, elk or buffalo intestines stuffed with tenderloin, fried deer liver	Buffalo, deer, elk, big horn sheep, mountain sheep & lambs, mountain lion, fox, badger, rabbit, goat & sheep organs, venison, antelope, wild boar
FINNED & SEAFOOD		Broiled trout	
WINGED		Roasted prairie chicken, grouse, crow gut, game stew	Wild game
GRAINS & FLOUR		Wild rice, cattail pollen flapjacks	Wheat, atole, tortillas, piki; breads: corn, kneel down, wild sage, adobe; blue corn griddle cakes & dumplings, blue cornmeal, chili fritter
SWEETS			Sweetbread, pumpkin-pinon cake or bread, fruit pies (paselitos), sprouted wheat pudding, sweet bread pudding, pumpkin candy, chocolate with honey

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003. 1991.

Table 7.6 TRADITIONAL FOODS OF SPECIFIC GREAT PLAIN AND SOUTHWESTERN AMERICAN INDIAN TRIBES<sup>1</sup>

TRIBES	COMMONLY CONSUMED FOODS
<b>BLACKFOOT:</b>	Fried yeast bread
<b>CHEYENNE:</b>	Batter bread, service berry (sacred food) up-side down cake
<b>COMANCHE, SHOSHONE &amp; KIOWA:</b>	Snakes, fried frog legs
<b>CROW:</b>	Chokecherry pudding
<b>HIDATSA:</b>	Stuffed sugar pumpkin
<b>NAVAJO:</b>	Ground cherry, Hollowstomach/Bristly Hidden Flower, Juniper berries, Manzanita, Sego-Lily flowers & bulbs, wild rhubarb, wolfberry; Rocky Mountain Beeweed, Mormon Tea, Navajo tea (Cota), Tumbleweed sprouts, wild celery, wild carrots/Queen Anne's Lace, wild potato; sheep & goat organs; goat & cow's milk; whole grain flour, ground sprouted grain flour, cornmeal tamales, yeast bread, pinto bean tacos, pinto beans with sheep fat
<b>TOHONO O'ODHAM:</b>	Mesquite beans, mesquite pod flour, sprouts of bloodroot amaranth, fruits of the prickly pear cactus, white and yellow tepary beans, wolfberries, mesquite pods, mustard seeds, cholla blossoms, acorns, lima beans, corn; grain-like seeds of an herb known as psyllium or plantago (may reduce risk factors among the diabetes-prone) <sup>2</sup>
<b>PIMA:</b>	Wolfberries, lycium, wheat berries, berry pudding, cactus flowers; wild spinach, amaranth or purslane wild greens; chorizo sausage & eggs, tripe, beef feet; flour tortillas, mesquite bean pudding, wheat kernels, mesquite pods

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003. 1991.<sup>2</sup> Cowen R. Seeds of Protection. Science News 1990:137:350-351

Table 7.7 TRADITIONAL FOODS OF THE WEST AMERICAN INDIANS AND NORTHWEST COASTAL TRIBES<sup>1</sup>

FOOD GROUPS		THE WEST: (Plateau Region) Sanpoil, Kutenai, Klamath, Flathead, Nez Perce; (California) Hupa, Pomo, Mohave, Yuki, Luiseno; (Great Basin) Ute, Paiute, Shoshone, Gosiute, Bannock	NORTHWEST COAST: Northern tribes: Haida, Tlingit, Tsimshian, Bella Bella; Southern tribes: Kwakiutl, Nootka, Salish; ALASKA: Eskimo, Aleut, Yupik and Inupiat
FRUITS & FLOWERS		California tribes: wild fruits & berries	Salmonberries, huckleberries, goose-berries, black currants, Oregon grapes, bearberries, wild rhubarb, crab apple, blueberries, raspberries, wild cranberry
VEGETABLES & HERBS		Plateau tribes: camas roots (relative of lily & onion) California tribes: wild greens; Great Basin: bulbs, roots and leaves of young bulrushes, shoots of thistle, squaw cabbage, clover, pulpy cactus leaves	Roots of ferns, lupine, rush camas (for flour), wild celery, purple clover roots, pigweed, glasswort; wild: onions, spinach, watercress, wild ginger, root & blossoms, fiddle-head fern, beets (19th century), Indian cress (nasturtiums), lamb's quarters, minor lettuce, dandelion greens, purslane, rose hips (rich in vitamin C), rose hip seeds (vitamin E & A); wapato- a Jerusalem artichoke-like tuber, wild turnips
LEGUMES & NUTS		California tribes: acorns; Great Basin: pinons	Hazelnuts
FOUR LEGGED		California tribes: deer, elk, rabbits	Deer, elk, bear, moose
FINNED		Plateau tribes: salmon	Herring, smelts, candlefish, salmon, halibut, cod, clams, mussels, oysters, abalone, crabs, limpets; fish smoked, dried & pressed in oil; seals, sea otters, whale
WINGED		California tribes: grasshoppers, hornet & yellow jacket grubs; Great Basin: grasshoppers, crickets, locust (eggs, larvae & chrysalides)	Roast wild ducks, grilled goose
GRAINS & FLOUR			Acorn: mush, flour, griddle cakes, dumplings
SWEETS			Honey
FATS			Fish or seal oil
OTHER		California tribes: army worms (small hairless caterpillars, ants)	Powdered berries or powdered skunk pillars), Angle worms; Great cabbage leaves were used as a thickener

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003. 1991.

Table 7.8 TRADITIONAL FOODS SPECIFIC TO THE WESTERN AMERICAN INDIANS AND ALASKAN TRIBES

TRIBES	COMMONLY CONSUMED FOODS
NEZ PERCE: <sup>1</sup>	Huckleberry, chokeberries, elderberries, wax currant, gooseberries, Hawthorne thornapple, service berries, Mountain tea, Koush, camas, Khemmes, kouse-kouse, wild carrot, early morel mushroom, bitter root, wild onions, yew; deer jerky, elk, moose, bear, salmon
ALASKANS: <sup>2</sup>	<ul style="list-style-type: none"> <li>Goose Grass or Maretail: added to soup or meat/fish broths; source of fiber</li> <li>Sea Lovage (wild celery): added to meat, fish &amp; soups; eaten as side dish with seal oil; source of vitamins A &amp; C</li> <li>Woolly Lousewort: eaten as sauerkraut; roots are eaten raw or added to stews &amp; soups; source of fiber</li> <li>Pallas Buttercup: cooked in seal, fish or meat broth; not eaten raw: source of vitamin C</li> <li>Wild Rhubarb: boiled and eaten as a side dish: source of vitamins A and C</li> <li>Sourdock: raw leaves used in salads; eaten as a cooked side dish: sources of Vitamins A and C; iron</li> <li>roots: willow roots, arrowroot plant, cotton grass roots, Eskimo or Indian potato,</li> <li>Popular dish: baked flounder, tom cod, tom cod liver with black berry akutaq and wild sweet potatoes: sources of protein, calcium, vitamins A, C and B-complex</li> <li>sources of iron: caribou, moose, seal &amp; seal liver, hare and mink, bear, beaver, beluga liver, reindeer, elder duck, ptarmigan, walrus, whitefish liver</li> <li>sources of calcium: bering cisco, blackfish, smelts, salmon, needlefish, bone marrow, fish head soup, tom cod, pike</li> <li>sources of Vitamin C: fireweed, cloudberry, sourdock, wild rhubarb, willow leaves, rose hips, berries: crowberry (blackberry), cranberry, blue bogberries, red currants, salmonberries (cloudberries)</li> <li>sources of vitamin A: duck eggs, caribou liver, herring (dried/poke) moose and seal livers, seal oil, sourdock, tom cod &amp; liver, wild greens: felt-y-leaved willow leaf, fiddle head fern, cow slip, cow parsnip, beach greens (spinach &amp; asparagus) false head plant, whitefish, liver and eggs</li> <li>other: wild rice, black seaweed</li> </ul>
OTHER: <sup>3</sup>	Berries: False Solomon's Seal, Oregon grape, blue elderberry, red elderberry, salal, evergreen huckleberry, red huckleberry, swamp gooseberry, thimbleberry, salmon berry, trailing wild blackberry

<sup>1</sup> Spirit of the Harvest: North American Indian Cooking by Beverly Cox and Martin Jacobs. Workman Publishing, 708 Broadway, NY, NY 10003. 1991.

<sup>2</sup> Gregory MM. Yupik Native Nutrition. Yukon-Kuskokwim Health Corporation, Bethel, Alaska, 1989.

<sup>3</sup> Keely PB, Martinsen CS, Hunn ES, Norton HH. Composition of native American fruits in the Pacific Northwest. JADA 1982;81:568-572. (prior to European contact)

## Food Sources of Macronutrients, Vitamins and Minerals

Tables 7.9-7.11 show the macro- and micronutrients<sup>27-29</sup> available in the foods commonly consumed by American Indians and Alaska Natives prior to European influence. These tables indicate that the foods hunted, fished and gathered by these populations (Tables 7.1-7.8) supplied the nutrients needed for growth, development, and maintenance. With few exceptions, the fruits and vegetable cited in these tables were wild.

**Table 7.9 TRADITIONAL AMERICAN INDIAN FOOD SOURCES<sup>1</sup> OF MACRONUTRIENTS<sup>2</sup>**

NUTRIENT	MAJOR FOOD SOURCES OF NATIVE AMERICANS*
<b>CARBOHYDRATES</b>	
Monosaccharides:	fruits, honey, corn syrup
Disaccharides:	molasses, maple syrup; milk & milk products
Polysaccharides:	
Indigestible	stalks and leaves of vegetables, outer covering of seeds, fruits
Partially digestible	Jerusalem artichokes, onions, garlic, legumes, fruits
Digestible	grains, vegetables (especially tubers and legumes)
Carbohydrate Derivative: (Ethyl Alcohol)	fermented liquors
<b>PROTEIN</b>	
	fresh tuna, fresh fish fillets, fresh salmon, eggs, sardines, meat, chicken, cabbage, milk, dry beans & peas
Essential amino acids:	egg, human's milk; meat, fish, beans, peas, sorghum, sweet potato, spinach; lentils, cornmeal, white potato, rice; peanuts; carrot
<b>FATS</b>	
Essential fatty acids:	
Arachidonic	animal fats; fish oils
Linoleic & linolenic	plant and some animal lipids
Oleic	all fats & oils
Other fatty acids:	
Arachidic	peanut oil
Gadoleic	fish oil
Palmitic	all fats & oils
Stearic	tallow, lard
Tetracosanic	brain lipids
Cholesterol:	egg yolk, liver, kidney, sweetbreads, brains, fish roe, oysters

1 Traditional foods provided in Tables 7.1-7.8.

2 Krause MV. Food, Nutrition and Diet Therapy, 4th ed. WB Saunders Co. Philadelphia. Pa. 1969.

\* prior to European influence

**Table 7.10 TRADITIONAL AMERICAN INDIAN FOOD SOURCES<sup>1</sup> OF MINERALS<sup>2</sup>**

NUTRIENT	MAJOR FOOD SOURCES OF NATIVE AMERICANS*
Calcium	milk & products, sardines, clams, oysters, turnip & mustard greens,
Choline	sea salt, seafood, meat, eggs
Chromium	meat (skin, fat, adrenal glands, brain & muscle)
Cobalt	green leafy vegetables (amount depends on soil)
Copper <sup>2,3</sup>	organ meats (liver, kidney), oysters, nuts, legumes, dried fruit, shellfish, poultry, animal tissue, mollusks, arthropods; pea seedlings; adrenal glands (Alaska natives); squash, cucumbers; mushrooms; spinach; mung bean seedlings; horseradish root
Fluorine	seafood, tea, bone meal, spinach,
Iodine	seafood, ocean fish, sea salt
Iron	liver, oysters, shrimp, kidney, lean meat, tongue, egg yolk, dried beans & peas, dried fruit, whole grains, dark green vegetables, dark molasses
Magnesium	whole grain, nuts, meat, milk, green vegetables, legumes
Manganese	blueberries, bran, nuts, legumes, meat, fish, poultry, milk foods
Molybdenum	legumes, grains, some dark green leafy vegetables, animal organs
Phosphorus	peanuts, poultry, fish, meat, oysters, milk, eggs, whole grains, legumes
Potassium	meats, fruits & vegetables
Selenium <sup>2,4</sup>	organ meats (liver, kidney, heart, spleen), meat, eggs, fish & shellfish, sunflower seeds, walnuts, pork, poultry, mushrooms, woody aster, gray's vetch
Sodium	sea salt, milk, milk products, eggs, meat, seafood, animal foods, celery, spinach
Sulfur	meat, fish, poultry, eggs, milk, nuts, peanuts, legumes, liver,
Zinc <sup>2,3</sup>	animal tissue, liver and other organ meats, shellfish, egg yolk, herring, milk, rabbit and meat muscle, snake (cottonmouth, moccasin)

1 Traditional foods provided in Tables 7.1-7.8.

2 Krause MV. Food, Nutrition and Diet Therapy, 4th ed. WB Saunders Co. Philadelphia. Pa. 1969.

3 Goodhart RS and Shils ME. Modern Nutrition in Health and Disease. 5th Edition. Lee &amp; Febiger, Philadelphia, Pa. 1973.

4 Gebhardt SE and Holden JM. Provisional on the Selenium Contents of Foods. Nutrient Composition Lab, ARS. Nutrient Data Research Branch. USDA. 1992.

\* prior to European influence



Table 7.11 TRADITIONAL AMERICAN INDIAN FOOD SOURCES<sup>1</sup> OF VITAMINS<sup>2</sup>

NUTRIENT	MAJOR FOOD SOURCES OF NATIVE AMERICANS*
Vitamin A Carotene	liver, kidney, fish liver oils, egg yolk, milk fat dark green leafy and yellow vegetables, carrots, sweet potatoes, squash, yellow fruit (peaches, cantaloupe) <sup>3</sup>
B <sub>36</sub>	grain germ, meat, organ meats (especially liver), white beans, white & sweet potatoes, poultry, walnuts, whole grains, milk, legumes, egg yolks, fish (perch, halibut, tuna, salmon) <sup>2</sup>
Vitamin B <sub>12</sub>	liver, kidney, milk and milk foods, meat, eggs
Biotin	liver, mushrooms, peanuts, milk, meat, egg yolk, most vegetables, watermelon, strawberries
Thiamin	lean meat, organ meats (liver, heart & kidney), fish, oysters, poultry, egg yolks, legumes, whole grains, potatoes, pork <sup>2,3</sup>
Riboflavin	milk & milk foods, organ meats (liver, heart & kidney), green leafy vegetables, eggs
Niacin	fish, liver, lean meat, poultry, many grains, eggs, peanuts, legumes, milk
Vitamin C	moose adrenal glands (Alaska Natives), oranges, tomatoes, melons, peppers, greens, cabbage, strawberries
Vitamin D	fish liver oils, egg yolk, liver, salmon, tuna, sardines
Vitamin E	grain germ oil, green plants, egg yolk, milk fat, meat (especially liver), nuts, corn oil
Folic Acid	plant & animal tissue, liver & other organ meats, lentils, dry beans, cow peas, spinach, asparagus, eggs, fish, dark green leaves, kidney, nuts, whole grains
Vitamin K	meat (especially liver), milk, eggs, fruits, green leafy vegetables, tomatoes, wheat bran, corn oils, green tea, turnip greens, cabbage, spinach, asparagus, watercress, research <sup>2,3</sup>
Pantothenic acid	plant & animal tissue; egg yolks, kidney, liver, salmon, potatoes (white and sweet), tomatoes, molasses, peanuts, walnuts <sup>2,3</sup>

1 Traditional foods provided in Tables 7.1-7.8.

2 Krause MV. Food, Nutrition and Diet Therapy, 4th ed. WB Saunders Co. Philadelphia. Pa. 1969.

3 Goodhart RS and Shils ME. Modern Nutrition in Health and Disease. 5th Edition. Lee &amp; Febiger, Philadelphia, Pa. 1973.

\* prior to European influence

Before discussing the contemporary eating habits of Native Americans, this next part gives an overview of the attitudes that were of importance to Native People, the historical factors that have impacted on their health and nutritional status, and the contemporary health concerns they face today.

### Traditional and Contemporary Attitudes about Health and Illness

Native Americans have traditionally cherished good health and longevity. They believed that the health and the well-being of each tribal member determined their community's productivity.<sup>30</sup> To them, a person in good health and well-being was *in a state of beauty or harmony*. In this state, all parts of the body functioned perfectly and exalted feelings of well-being were felt. A person not in a "state of harmony" was considered either *sick or ill*. *Sickness* could be physical, mental, social, or environmental in nature. Physical sickness included colds, burns, skin rashes, conditions associated with the menstrual cycle and pregnancy, broken bones, and other similar occurrences. *Illness*, considered more serious than sickness, was disharmony caused by domestic strife, mental anguish, bad dreams, or misfortune.<sup>31</sup> Illness came about slowly, lingered for a long time, and had no discernable cause.<sup>32</sup>

Numerous tribes integrated health and sickness concepts with their basic religious precepts, which were based upon *mythology*. Myths defined their social origins, relationships with the supernatural, and the nature of the cosmos. Tribes believed that supernaturals made the worlds and aided them in overcoming numerous environmental and social hardships. Furthermore, they believed that each mundane act was related to a mythological event which occurred in the past and therefore deserved its proper respect in the present. *Performing prescribed behaviors guaranteed them spiritual, social, and physical well-being* and trouble, of any kind, was a direct consequence of a breach of the "prescribed order."<sup>31</sup> Native Americans believed that either transgressions of prescribed behavior or evil spirits caused a person's disharmony,<sup>30,31</sup> and that disharmony of any kind affected the entire community by removing the person from his or her functioning role.<sup>30</sup>

Over time, theories of illness led to logical methods of curing. Some tribes believed that illness came from the meat of animals that had not been treated with proper respect.<sup>33</sup> Other tribes believed illness was the consequence of mistreating animals and that certain plants would counteract the conditions.<sup>34</sup> A person who could heal the body and spirit of others was revered. Native People believed that the healer was given power from the spirits and herbal medicines<sup>26</sup> because he had learned to control or counteract the negative powers from the human or spiritual world that caused illness. The healer often used song or chant to conquered negative spirits; thus, his spoken words had incredible power at a time when Indian tribes had no written language.<sup>30</sup>

Most Native American tribes have communicated their attitudes about health and illness to younger generations through ceremonial participation and storytelling. As a result, the old attitudes about health, illness, and healing are held by most Native People today. However, some non-Native health care providers who treat the illnesses of these tribal communities do not know about or understand these attitudes. Many non-Native health care providers do not understand that the actions and reactions of their Native American patients are influenced by

their cultural and religious beliefs. This was first evident in a 1955 study designed to evaluate the Anglo doctor's role in the healing of Navajos. It was found that Anglo doctors placed far greater emphasis on the various cultural beliefs of Navajos that blocked their acculturation rather than recognizing the appropriate role of the Anglo doctor in the Navajo healing process, and the range of behaviors permitted by the Navajo when being treated for illness.<sup>31</sup>

Today, the healing process of most Native tribes corresponds with the Anglo healing categories: a) recognition of disease, b) diagnosis, c) symptomatic treatment, d) etiological cure, and e) prevention. However, this is where similarities cease. One major difference between the cultures is the Native American's *concept of time*. For instance, Native People believe that symptoms or the manifestations of a disease that occurs in adulthood may have happened because of contact with the causal agent during childhood (a snake, negative spirit, or demon). Another major difference is that Native Americans rely on oral communication with the spirits to guarantee well-being when symptoms of illness persist. This communication, or "sing" is also used for prevention when it is known that an individual will come into contact with objects or malignant forces. Native Americans have traditionally used the "sing", herbal medicines, and tribal medicine men as *immunization prevention measures*. Prophylaxis or avoidance behavior has not been used because it was thought that the possibilities of contamination were too great to avoid. Many Native Americans still tend to rely on these "immunization preventive techniques" and view their own transgressions with a certain degree of equanimity rather than lead a rigid life. Most tribes use the "sing", their tribal healers, and the Anglo doctor. Their past fear of coming in contact with the dead in hospitals and clinics has lessened, and they now more readily accept the Anglo doctor's role in their healing process. However, Anglo doctors are still relegated the limited role of "the treater of symptoms rather than the curer." Therefore, it is understandable why antibiotics and other quick pain killers are more popular than sustained medical care and why Native People go to Anglo doctors primarily for symptomatic treatment.<sup>31</sup>

### Historical Events that Impacted on Native American Health Status

Prior to contact with the Europeans, most American Indians were generally healthy, well-formed, and relatively well-nourished people.<sup>35</sup> However, throughout the colonial period of American history, disease was a major factor in Indian-white relations. During the 1800s, some Indian tribes were made dependent domestic nations (Cherokee nation vs. Georgia, 1830 and Worcester vs. Georgia, 1831). This meant that they had no power over their own rights and had to depend on the federal government for food and medicine.<sup>36</sup>

By 1849, most Native Americans were removed from their traditional homes and forced onto reservations by the War Department so that western lands could be opened for white settlers.<sup>37</sup> Indian attempts to farm were largely unsuccessful because the arid and nutrient-poor soil on reservations limited their ability to raise food crops, or provide other adequate means of self-support.<sup>10</sup> The Indian nations were no longer permitted to hunt, fish, or gather their food freely and extreme changes took place in their health status. With the sporadic distribution of army food (moldy beef, flour, sugar and coffee) and the disappearance of the buffalo (killed by non-Natives), the Indians suffered from tuberculosis and other diseases.<sup>37</sup> Malnutrition ran rampant, especially among children and infants. The sight of pot bellies, stooped shoulders, and winged scapulae were common place.<sup>10</sup>

In 1887, the Dawes Act provided for the division of Indian lands on the basis of individual ownership and for the ultimate assimilation of native people into American society as individual landowners. In seven years, Indian-owned lands decreased from 150 million acres to 50 million acres. Severe overcrowding of Indian families on homesteads resulted in farms that could not sustain them.<sup>38</sup>

In 1928, the Bureau of Indian Affairs reported on the living standards, education, and health of Indians and concluded that the allotment of Indian land had indeed created conditions of dire poverty. The report singled out the meager food supply as the most important factor affecting the health of Indians. Diet staples included meat or fish, bread, beans, sugar, and coffee or tea, but no milk or eggs. Vegetables and fruit were eaten by some tribes that raised corn, squash, and melons or gathered wild fruit, roots, and nuts in season. Generally, their diet lacked quantity and quality. Such conditions existed on reservations and in Indian boarding schools, and malnutrition continued to mark many Indian children (Meriam Report, 1928).<sup>39</sup> In 1934, The Wheeler-Howard Act made it possible for Indian tribes to organize themselves as legally recognized bodies, and to deal with the government. The Hopi-Navajo Rehabilitation Act of 1949 provided assistance to native people who wanted to leave the reservation and move into urban areas<sup>40</sup> where there were better economic opportunities. In 1953, the House Concurrent Resolution 108 specified that if tribes met certain criteria they should become citizens of the United States on the same basis as all other citizens.<sup>41</sup> Two years later, the Bureau of Indian Affairs was transferred from the Department of the Interior to the Public Health Service in the Department of Health, Education and Welfare (DHEW), and a new era of Indian health began.<sup>42</sup>

### Contemporary Nutrition-Related Health Concerns of Native Americans

By 1890, the original North America Indian population had decreased from 18 million to 228,000. One hundred years later, the population approached 2 million. This recovery is due in part to the attention paid to Indian health care.<sup>43</sup> Since the mid-1950's, death rates among American Indians with gastrointestinal diseases, influenza and pneumonia, and natal-based conditions have decreased drastically. However, statistics indicate that Indians are still at greater risk for certain health problems than is the general public.<sup>44</sup>

As of 1987, the leading causes of death among Native People living on reservations were heart disease, cancer, injuries, stroke, liver disease, diabetes, pneumonia/influenza, suicide, homicides and chronic lung disease.<sup>45</sup> Of these, heart disease, cancer, and diabetes are nutrition-related (Table 7.12). Alcoholism is included because it is associated with liver disease and poor eating habits.<sup>46</sup> Table 7.13 shows the age-adjusted mortality rates for cancers common among Native Americans in Indian Health Service Areas between 1984-88, namely, cancers of the breast, colon and rectum, cervix, lungs, pancreas, prostate, and stomach. By specific region, high rates of liver and kidney cancers were observed among Billings males, and ovarian cancer among Billings females. A high rate of gallbladder cancer was also observed among Navajo females; and high rates of liver cancer among males and gallbladder cancer among females living in the Tucson IHS area.<sup>47</sup> Table 7.13 indicates that the mortality rates in these IHS areas differ substantially. Chapter 2 in Section I of this publication addresses the problem areas of data collection that make deciphering these differences difficult, namely, racial misclassification, undercounting, underrepresentation, and coding. Errors in data collection are *partially* responsible for these observed differences.

However, the overall high rates of cancer among Native Americans may also be due to the fact that many Indian people still don't believe in "white" health care because too often it has not cured their disease,<sup>48</sup> or they are not accessible to treatment.

In addition to the chronic diseases cited in Table 7.12, obesity remains a significant health problem among Native People for several reasons. Aside from the socioeconomic issues, limited quantities of nutrient-dense foods, inactivity, and high-fat, high-sugar food choices, many Native People are still not convinced that excessive weight is associated with chronic diseases.<sup>49,50</sup> Similarly, while most tribal communities consider alcoholism to be their most important health problem and responsible for over 90% of all crimes committed in tribal communities, alcohol abuse is not generally viewed as a major risk factor for cancers of the mouth, throat, esophagus, large bowel, pancreas, liver, kidney, and breast, obesity, and other chronic diseases. These attitudes indicate there is *a need to educate this culture about diet and cancer while reinforcing their traditional cultural beliefs.*

## CONTEMPORARY CONSUMPTION PRACTICES OF NATIVE AMERICANS

Over the last thirty years, the traditional foods consumed by the ancestors of American Indians and Alaska Natives been replaced by processed and commercially prepared foods; the variety and quality of which have been limited. And, foods traditionally prepared over slow fires have been replaced with pan or deep-fat frying cooking methods. Although today's Native American populations are encouraged to incorporate more of their traditional foods in their diet,<sup>51,52</sup> these cultures have been slow to adopt the healthier habits. This may be due in part to the availability of traditional foods or the time it takes to prepare them.

The bibliography in Appendix F lists the limited studies that have attempted to collect dietary information from Native Americans that would permit the investigation between their rates of disease prevalence and eating habits. Without the cooperation, assistance, and participation of the tribal councils and community members, the collection of reliable data on health and nutrition indices of Native Americans living on reservations is limited.<sup>53</sup> Few if any attempts have been made to survey Native Americans who live among the general population, which according to the 1990 Census<sup>54</sup> is the majority (70%) of this culture. Furthermore, surveying the non-reservation segment of this population is difficult because those who have left the reservation in an attempt to "merge" with non-native cultures often return. When they leave the general population, they may return to a different reservation or live with family or friends. Unless a survey is designed to classify Native Americans properly, tracking these individuals for survey participation would be extremely difficult.<sup>53</sup> The surveillance and nutrition research needs to adequately monitor the health and nutritional status of this culture are addressed in Chapter 8.

There are tremendous gaps in our knowledge about the contemporary consumption practices of the numerous Native American tribes and Alaska communities. Presented here is an overview of what is presently known about the food selections of Native Americans who live on four reservations and are recipients of USDA's Food Distribution Programs.

Table 7.12 Age-Adjusted<sup>1</sup> Mortality Rates<sup>2</sup> of Nutrition-Related Diseases in IHS Area, 1986-88

	Heart Disease		Cancer		Diabetes		Alcoholism	
	Deaths	Rate	Deaths	Rate	Deaths	Rate	Deaths	Rate
U.S. All Races (1987)	760,353	169.6	476,927	132.9	38,532	9.8	15,909	6.0
All IHS Areas	3,854	156.1	2,344	99.8	683	29.7	742	32.7
9 Areas <sup>3</sup> (1986-88)	2,290	170.8	1,492	116.3	443	36.1	580	45.8
Aberdeen	452	287.7	228	151.1	52	35.4	99	69.9
Alaska	275	170.1	260	167.0	10	6.4	37	22.5
Albuquerque	122	103.8	107	100.1	52	51.7	60	56.4
Bemidji	273	267.5	152	148.8	36	36.3	31	32.8
Billings	207	217.7	132	148.0	22	24.2	51	57.8
Nashville	168	173.7	99	105.4	42	47.5	21	24.3
Navajo	389	98.9	312	85.8	89	26.5	127	36.6
Phoenix	320	163.2	163	85.7	106	58.4	129	64.5
Tucson	84	203.2	39	97.2	34	96.9	25	66.6

<sup>1</sup> Age-adjusted rate per 100,000 population. Rates based on a small number of deaths should be interpreted with caution.

<sup>2</sup> Regional Differences in Indian Health. Indian Health Service. DHHS:PHS:IHS:OPEL: Div. of Program Statistics. 1991.

<sup>3</sup> Three IHS areas (California, Oklahoma, and Portland) have been deleted due to underreporting of Indian race on death certificates.

Table 7.13 Age-Adjusted<sup>1</sup> Mortality Rates<sup>2</sup> of Nutrition-Related Cancers in IHS Area, 1984-1983<sup>3</sup>

CANCER SITES	LUNG		COLORECTAL		BREAST	CERVICAL		PROSTATE		STOMACH		PANCREAS	
	M	F	M	F		M	F	M	F	M	F	M	F
US, All Races	74.2	27.3	24.5	17.1	27.3	3.1		24.0		7.3	3.3	10.1	7.2
Aberdeen	68.7	45.0	16.3	*	24.0	13.6		25.4		*	*	13.3	11.8
Alaska	75.5	68.5	19.1	33.0	14.7	*		*		11.9	*	9.0	10.7
Albuquerque	18.8	*	*	9.7	10.4	9.6		28.8		15.7	9.7	12.2	*
Bernidji	63.4	40.7	23.3	10.8	19.0	*		22.9		*	10.6	10.1	*
Billing	65.3	65.7	11.8	*	14.6	17.4		31.5		*	*	*	*
Nashville	41.8	25.1	10.8	11.9	25.5	11.6		11.1		*	*	7.7	*
Navajo	11.4	*	*	*	15.5	9.3		8.7		13.9	11.6	7.8	*
Phoenix	17.2	11.5	6.6	10.1	9.5	7.5		13.9		*	*	6.2	*
Tucson	25.9	13.5	*	10.4	13.7	*		7.9		20.5	*	*	*

<sup>1</sup> Rates per 100,000 per year adjusted to the 1970 U.S. standard population.<sup>2</sup> Cancer Mortality Among Native Americans in the United States: Regional Differences in Indian Health, 1984-1988 and Trends Over Time, 1968-1987. DHHS:PHS:IHS:Office of Health Programs, Cancer Prevention and Control Program.<sup>3</sup> Three IHS areas (California, Oklahoma, and Portland) have been deleted due to underreporting of Indian race on death certificates.

\* No statistics available.

### The Food Distribution Program on Indian Reservations (FDPIR)

In 1936, the U.S. Department of Agriculture established the *Needy Family Program*. It was the first federal food distribution program made available to Native Americans living on reservations. Families received packages of rice, cornmeal, flour, dry beans, and nonfat dry milk. In 1977, the Food Stamp Act created the *Food Distribution Program on Indian Reservations (FDPIR)* to replace the Needy Family Program. The original five food packages were expanded to include 60 types of foods from four basic food groups: meats, vegetables-fruits, dairy and grains. The FDPIR, which has provided a variety of food commodities in lieu of food stamps, has been a major source of nourishment for residents of reservations who could not raise their own livestock or grow fruits, vegetables, or grain foods.<sup>55</sup>

As of 1990, 19.8 percent of all Native Americans lived on one of 215 Federal reservations.<sup>54</sup> In a 1990 report evaluating USDA's Food Distribution Program, it stated that approximately 65-70% of the Native American living on reservation received either food commodities (Table 7.14) or food stamps. A typical FDPIR household included an average of 3.2 persons; 40% of the families were one or two-person households, and 8.5% were single-parent homes. The households generally included children and older adults aged 60 and over. The average level of education attained was the 10th grade. Over fifty percent of the adults worked, were looking for work, or were laid off and were looking for work. Most of the households were poor by any conventional standard and experienced transportation difficulties.<sup>55</sup>

Most FDPIR participants had to rely on food purchases, home food production, and other USDA programs, in addition to the program commodities to meet their dietary needs. When asked about the amounts of food provided by the program, seven out of 8 households said they had enough; others did not have enough to eat one day out of every 5 or 6 days. Although most households (except for some of those who live in the North and Southwest) had adequate food preparation and storage facilities, (e.g., running water, electricity, and refrigeration) over one-half of all the households had one adult with one or more nutrition-related health problem; and more than one out of four households had at least one member on a special diet.<sup>55</sup>

Before USDA provided food commodities to Native Americans on reservations, several studies showed that children had minimal intakes of calories, calcium, iron, and vitamins A and C. Although the original FDPIR food packages were not nutritionally based and evolved from the commodity distribution program, anemia decreased when the supplemental commodities were first introduced. But, the original FDPIR package only supplied about 50% of the recommended nutrient levels (except for vitamins A and C) needed to maintain health and prevent disease. Thirty-seven percent of the calories came from fat and the dietary fiber content was minimal.<sup>56</sup> Even though these foods improved the diets of many American Indians, insufficient variety and quantities of nutrient-dense foods have contributed in part to the health problems, low-birth weights of infants, shorter but heavier children, and increased mortality rates observed among Native Americans for the last twenty-five years. It was not until the early 1980s when nutrition became a national issue that the food packages were scrutinized. Current USDA commodities now include surplus and purchased foods and contribute 101% of the RDA for calories and 34% of the calories come from fat.<sup>56,57</sup> However, Native Americans and Indian health officials still express concern about the sodium



**Table 7.14 Foods Recommended by the 1990 Dietary Guidelines for Americans and Provisions of the USDA FDIPIR Food Commodities**

1990 DIETARY GUIDELINES FOR AMERICANS <sup>1</sup>	1990 USDA FDIPIR FOOD COMMODITIES <sup>2</sup>
<p><b>2-4 FRUITS AND 3-5 VEGETABLES</b> - Eat</p> <ul style="list-style-type: none"> <li>- a variety of dark yellow/orange fruits and vegetables, and dark leafy green vegetables:</li> <li>- apricots, peaches, cantaloupe, melon, oranges</li> <li>- lemons, carrots, squash &amp; sweet potatoes</li> <li>- broccoli, spinach, kale mustard, collard &amp; turnip greens, brussels sprouts, cabbage &amp; and green peppers</li> </ul> <p><b>2-3 DIFFERENT MEATS OR SUBSTITUTES</b> - Eat</p> <ul style="list-style-type: none"> <li>- more fish and poultry and less red meat</li> <li>- small amounts of lean, trimmed red meat</li> <li>- small amounts of skinless poultry and cooked beans or peas as substitutes</li> <li>- use egg whites in scrambled eggs or pancakes</li> </ul> <p><b>2-4 DAIRY FOODS</b> - Eat</p> <ul style="list-style-type: none"> <li>- fewer whole milk dairy foods such as milk, cheese, yogurt, and ice cream</li> <li>- more low fat or skim milk dairy foods</li> </ul> <p><b>6-11 GRAIN FOODS</b> - Eat</p> <ul style="list-style-type: none"> <li>- more whole grain breads and cereals</li> <li>- fewer sugar-coated and fruit-flavored cereals</li> <li>- fewer white flour breads and rolls</li> <li>- more brown rice and whole wheat pastas</li> <li>- less refined sugar foods such as sugar, jam, jelly, syrups, sodas and candies</li> </ul> <p><b>LIMIT INTAKE OF VISIBLE FATS AND OILS</b> - Eat</p> <ul style="list-style-type: none"> <li>- fewer desserts, cakes, cream pies, cookies, candies and pastries</li> <li>- limit fried foods</li> <li>- limit gravies</li> <li>- limit the amount of animal fat and fat dripping used on and in the preparation of foods</li> </ul> <p><b>LIMIT INTAKE OF SALT, SMOKED &amp; PICKLED FOODS</b></p> <p><b>LIMIT DAILY INTAKE OF ALCOHOL</b></p>	<ul style="list-style-type: none"> <li>- <b>CANNED FRUIT:</b> (juice &amp; syrup packed): apricots, applesauce, fruit cocktail, pears, plums, grapefruit sections, pineapple; pumpkin, cranberry sauce, peaches</li> <li>- <b>DRIED FRUIT:</b> prunes &amp; raisins</li> <li>- <b>JUICES:</b> apple, grape, grapefruit, orange, pineapple, tomato</li> <li>- <b>VEGETABLES:</b> carrots, corn-creamed &amp; whole kernel, green beans, green peas; white potatoes: canned whole, dry flakes &amp; dry granules; canned sweet potatoes, canned spinach; tomatoes: canned whole &amp; sauce</li> <li>- <b>MEAT:</b> beef, meatball stew, canned luncheon meats, canned pork, turkey &amp; chicken</li> <li>- <b>FISH:</b> canned salmon &amp; tuna</li> <li>- <b>LEGUMES:</b> beans: black, brown, bayo, blackeyed, great northern, kidney, lima, navy, pinto, cowpeas</li> <li>- <b>NUTS/SEEDS:</b> sunflower seeds, peanuts &amp; peanut butter</li> <li>- <b>EGGS:</b> dry mix</li> <li>- <b>CHEESE:</b> American processed</li> <li>- <b>MILK:</b> evaporated, dry whole</li> <li>- <b>CEREALS:</b> oat, corn, rice &amp; wheat, Kix; farina, rolled oats</li> <li>- <b>GRAIN FOODS:</b> bulgur, corn grits &amp; meal; rice: white, brown &amp; instant</li> <li>- <b>FLOUR PRODUCTS:</b> macaroni, spaghetti, Bisquick, soda &amp; saltine crackers; flour: white, masa corn &amp; whole wheat</li> <li>- sweet butter, vegetable shortening, corn oil, corn syrup &amp; honey</li> </ul>

<sup>1</sup> Nutrition and Your Health: Dietary Guidelines for Americans, U.S. Departments of Agriculture and Health and Human Services, 1990.<sup>2</sup> Nutrient Composition of Food Available from USDA Food Distribution Program on Indian Reservations. Data compiled from the USDA, FNS Computerized Food Package Modeling System. Nutrition and Dietetics Section, Indian Health Service, Public Health Service DHHS. April 1990.

and fat content, the limited variety of commodity food items, and the need for expanded nutrition education services.

Providing commodities through FDPIR appears to be less expensive than providing food stamps to eligible households. However, the lack of variety in the FDPIR limits the types of foods chosen by participants (Table 7.15). It has been observed that the combined availability of FDPIR and the Food Stamp Program would provide more flexibility and a better level of service for American Indians than either program would individually.<sup>55</sup>

Table 7.15 Foods most often selected by participants of the USDA Food Distribution Program on Indian and Alaskan Reservations<sup>1</sup>

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<b>FRUITS</b>	Canned: peaches, fruit cocktail, pears, apricots; raisins; Juices: orange, apple, grape & tomato
<b>VEGETABLES</b>	Canned: whole kernel & cream-style corn, green beans
<b>MEATS</b>	Canned: beef, luncheon meat, chicken
<b>FISH</b>	Tuna
<b>LEGUMES</b>	Beans: pinto, great northern, baby lima; peanut butter
<b>DAIRY</b>	Evaporated milk, cheese
<b>CEREALS</b>	Corn cereal & rice cereals; oatmeal & farina
<b>GRAIN FOODS</b>	White flour bread products & macaroni
<b>FATS &amp; SUGAR</b>	Vegetable shortenings & oil, corn syrup & honey

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1 Food Assistance Programs: Nutritional Adequacy of Primary Food Programs on Four Indian Reservations. GAO/RCED-89-177, 9/1989.

### Food Stamp Program Participants

Native Americans who live on reservations and participate in USDA's Food Stamp Program do not receive commodities from the FDPIR program. According to USDA, the Food Stamp Program was designed to benefit Native Americans by providing households with no countable income an adequate quantity of food and nutrients for an entire month. However, most food stamp households have some countable income that they use for food purchases. The food stamps are nutritionally based on USDA's 1983 Thrifty Food Plan and take into consideration the food consumption practices of the family, food prices, nutrient composition of foods, and human nutritional requirements as established by the National Academy of Sciences in 1980.<sup>55</sup> However, these Native Americans are exposed to the same food outlets as the general population--fast foods, convenience stores, and vending machines that too often provide foods that are high in fat, sodium, and sugar but low in nutrients and fiber. Food stamp recipients may purchase any food item, regardless of its cost or nutrient content, which makes it difficult to determine their nutritional status in the absence of an acceptable monitoring system.<sup>58</sup>

### Obstacles to participating in the USDA Food Stamp Program

An intimidating and lengthy food stamp application process, transportation problems, or treatment given to persons with a reliable vehicle deter many American Indians from applying for food stamps. For example, some Native People have no or only occasional access to a vehicle, making it difficult to pick up their food packages or to travel to a grocery store (20 miles or more from home). For those who do have cars, transportation may be

costly (gas averages 50% higher on reservations than off) or difficult in inclement weather. Unlike the FDPIR program, a reliable vehicle in some families may disqualify the family for food stamps, if the value of the vehicle is too high.

### **Obstacles to Meeting the 1990 Dietary Guidelines**

Participation in the FDPIR program does not guarantee Native Americans nutrient-dense foods, proper nourishment or that the 1990 Dietary Guidelines will be met since this program is a supplemental food source. It was not intended to provide a 30-day supply of food; recipients are expected to purchase a portion of their monthly food supply. For Native Americans participating in the Food Stamp program, the purchasing power of the stamps depends upon reasonable food prices on and off the reservations, accessibility to grocery stores with an ample nutrient-dense food supply, and the appropriate use of the stamps by participants. These situations pose problems for Native People who are dependent on commodities or live in remote areas of the country. Too often Native Americans supplement the food commodities items foods from the local grocery store, convenience store, or vending machines that provide refined sugar and fats (sodas, sweets and desserts, fatty hamburgers, and processed white bread products) rather than fiber, vitamins, and minerals.<sup>55</sup> This may occur because healthier foods are not available or are available in limited quantities.

For the majority of Americans, the *1990 Dietary Guidelines* provide a sound foundation for disease prevention and health promotion. However, how practical are the guidelines for specific population groups where suggested foods are unavailable or too expensive to purchase? The following is an overview of the 1990 Dietary Guidelines and the food commodities made available to Native Americans by USDA (Table 7.14), and why Native Americans may have a problem meeting these Guidelines if the commodities are not supplemented.

### **Eat a Variety of Foods**

This guideline recommends consuming a variety of foods, rather than a few highly fortified foods or supplements, for the energy, protein, vitamins, minerals, and fiber needed each day. Americans are advised to eat different foods from the fruit, vegetable, meat, dairy, and grain food groups since a variety of these foods will provide ample macro- and micronutrients that no single food can supply to maintain good health. The guidelines also recommend limiting the intake of fats, sweets, salt, and alcohol.<sup>6</sup> About 30% of all cancers and possibly other chronic diseases could be reduced if people ate a variety of fresh fruits, vegetables, whole grain cereals and breads, lean meats, poultry, fish, beans, and low-fat dairy products each week.<sup>59</sup>

The current USDA food commodities, although improved, do not provide the variety of foods in each of the five food groups recommended in the *1990 Dietary Guidelines* shown in Table 7.14; nor do they provide an ample selection of low-fat foods, whole grain foods, fresh fruits and vegetables, or those foods recommended by the National Cancer Institute (high-fiber foods, vitamins A and C rich foods, cruciferous vegetables). Healthy commodities, such as water and juice packed fruits are available but the quantity of these foods are restricted.<sup>55</sup> Although Native Americans are not required to take food commodities that are high in fat or sugar,<sup>55</sup> the limited variety may encourage Native People to choose these foods.

Limited variety narrows the possibilities of obtaining the nutrients needed for health maintenance and prevention of certain chronic diseases.

### Maintain a Healthy Weight

Being too thin or overweight can cause health problems. In our world today, excessive fatness or obesity is the most common form of malnutrition and it is considered a major health problem among the general population. Obese individuals are at a greater risk of developing heart disease, high blood pressure, diabetes, and cancers of the colon, gallbladder, breast, endometrium, ovary, and prostate than persons who maintain their "suggested weight."<sup>6</sup> A healthy percentage of body fat for adults in their thirties is 12 percent for males and 19 percent for females.<sup>2</sup> After age 30, obese non-Indian male adults reach a peak of 39% and females, 50%.<sup>60</sup> It has been estimated that the range of fat content for all American Indians is between 30-60% of their total body weight.<sup>55</sup> Too much body fat around the chest and waist is believed to be an indicator of diabetes and coronary heart disease, and a greater health risk than excess fat in the hips and thighs.<sup>61</sup> The fat placement on Native Americans is generally in the chest and waist areas.<sup>53</sup>

Obesity among Native Americans results in part from eating too many foods prepared with fat and sugar commodities and/or from selecting similar foods purchased from local groceries, convenience stores, and vending machines.<sup>55</sup> A lack of routine exercise is another major contributor to their obesity-- a situation that is common to general population. Table 7.16 shows the "suggested" body weights for non-Native adult men and women in the general public by height and approximate energy expenditures for different activities.<sup>6</sup> This table is provided only as a guide since data on height, weight, and body mass index are not available for most Native American tribes.

Table 7.16 Suggested Body Weights for Non-Native Adults and Activities to Reduce Weight<sup>1</sup>

Height with no shoes	Weight in Pounds Without Clothes		Approximate Energy Expenditure by a Healthy Adult Weighing about 150 Pounds	
	Men	Women	Activity	Calories burned per hour
4' 10"		92-121	Lying quietly	80-100
4' 11"		95-124	Sitting quietly	85-105
5'		98-127	Standing quietly	100-120
5' 1 "	105-134	101-130	Walking slowly, 2 1/2 mph	210-230
5' 2 "	108-137	104-134	Walking quickly, 4 mph	315-345
5' 3 "	111-141	107-138	Light work:	125-310
5' 4 "	114-145	110-142	cleaning house	
5' 5 "	117-149	114-146	office work	
5' 6 "	121-154	118-150	shopping	
5' 7 "	125-159	122-154	Moderate work:	315-480
5' 8 "	129-163	126-159	biking 9 mph	
5' 9 "	133-167	130-164	jogging 6 mph	
5' 10"	137-172	134-169	scrubbing floors	
5' 11"	141-177		weeding gardens	
6'	145-182		Heavy work:	480-625
6' 1 "	149-187		fast dancing	
6' 2 "	153-192		basketball, swimming	
6' 3 "	157-197		chopping wood	
			cross-country skiing	
			running 7 mph	
			spading garden	

<sup>1</sup> Nutrition and Your Health: Dietary Guidelines for Americans: Maintain Desirable weight. Home and Garden Bull. No. 232-2. 1986. USDA. Human Nutrition Information Service. Washington, DC: US Government Printing Office. 1990.  
Note: For women 18-25 years, subtract one pound for each year under age 25.

### **Choose a Diet Low in Fat, Saturated Fat, and Cholesterol**

Many nutrition authorities now agree that individuals need to reduce their daily fat intake to 30% or less of total calories. Diets high in fat, saturated fat, and cholesterol are linked to increased risk of coronary heart, obesity, and some forms of cancer.<sup>2</sup> A consistent intake of high fat foods also increases the risk of the colon, gallbladder, breast, endometrium, ovary, and prostate cancers (Chapter 6). During the last twenty years, the food selections of most Americans have contributed 36-38% fat to their total caloric intakes.<sup>58</sup> Similar fat intakes were consumed by Native Americans who participated in the USDA commodities program on reservations during the early 1980s.<sup>55</sup>

Although Native Americans living off the reservation have a greater variety of nutrient-dense foods to choose from than persons living on reservations, they also have a greater variety of refined sugar and high fat food items at their disposal. To meet the recommendation for daily fat intake, Native Americans in the general population should: <sup>6</sup>

- . eat lower-fat dairy foods.
- . use egg whites instead of yolks in egg dishes.
- . limit or omit fried foods, especially foods deep fat fried with lard.
- . broil or roast meats, poultry, and fish on a rack and discard the fat drippings.
- . bake, boil, poach, steam, or broil using moderate heat, not high, or cook in a microwave oven.
- . eat more fish, and chicken with the skin removed, and less red meat.
- . discard the visible fat on meat.
- . limit the intake of non-visible sources of fat such as doughnuts, pastries, cakes, cream pies, danish, cookies, and chocolates.
- . skim the fat from soups, sauces, and stews, when possible.

For those living on reservations, dietary fat in USDA commodities comes from canned beef or pork products (i.e, Spam), luncheon meats, whole milk, cheese, butter, vegetables shortenings, oils, and peanut butter. Few, if any, lower-fat alternatives to these commodities are provided.<sup>57</sup>

### **Choose a Diet with Plenty of Vegetables, Fruits and Grain Products**

The *1990 Dietary Guidelines* recommend eating more vegetables, including legumes (dried beans and peas; fruits; and breads, cereals, pasta and rice. These foods are sources of important vitamins, minerals, fiber, and complex carbohydrates. The consumption of fiber from natural food sources rather than from supplements is emphasized because some of the benefits of high fiber foods may be in the food, not necessarily in the fiber alone.<sup>2,6</sup> These foods include pastas; grains (rice, whole wheat, cracked wheat, bulgur, oatmeal, whole cornmeal, brown rice, whole rye, and scotch barley); legumes (seeds, dry beans, peas, nuts); and starchy vegetables (potatoes, corn, peas, lima beans). Consumption of non-starchy fruits and vegetables is also recommended because these foods often contain chemopreventive nutrients such as carotenoids, selenium, vitamin C, and vitamin E.<sup>5</sup>

According to the data from the second National Health and Nutrition Examination Survey (1976-80), 90% of the Americans surveyed ate an average of about 11 gram of fiber

a day. Major sources were vegetables (28%), bread/crackers (19%), and fruit (17%). Only 24% of the total fiber intake came from grain foods and only 9% of the population met the NCI 5-A-Day recommendation.<sup>62</sup>

Although there are few data on the fiber intake of Native Americans living off reservations, the report evaluating the USDA commodities provided to persons living on reservations suggests that their fiber intake was lower than that of the U.S. average.<sup>55</sup> This was probably due to the fact that there is a limited variety of recommended whole-grain fiber foods, and the majority of commodity fruits and vegetables are canned, not fresh. Whole-grain flour, brown rice, and variety of dried legumes are provided in the commodities package, however, there are no prepared whole-grain items available. Preparing baked-goods (breads, rolls, muffins) is time-consuming and often not an option in families where the meal preparer must also support the family. Thus, bread flours are either not chosen or not utilized. The commodities would be improved by the addition of fresh produce and prepared whole-grain foods; however, transportation, storage, distribution, and refrigeration problems are vast in Indian country. If Native Americans are taught how to cultivate and tend gardens and store the foods in facilities that are available, some of these problems could be minimized.

### **Use Sugar Only in Moderation**

Although sugar supplies energy, it provides minimal amounts of macro- and micronutrients. Major sources of sugar are white or brown table sugar, honey, corn syrups, molasses, jellies and jams. Natural sweeteners found in nature include glucose, dextrose, fructose, sucrose, lactose, and maltose. Both sugars and starches (from vegetables and bread products) break down into sugars. Corn-base sweeteners (corn syrup) are added to foods in large amounts during processing for flavor and as a preservative. Sticky or chewy sugary foods that contain refined sugar are often also sources of fats.<sup>6</sup>

Too much sugar generally results in tooth decay. The frequent consumption of sweets also contributes to obesity which is associated with diabetes, and heart disease--health conditions common among older Native Americans. Recently, it has been observed among very young Native American children in the Southwest that the large quantities of soda they drink are causing tooth decay and obesity (Breuninger, 1993).<sup>63</sup> Too often, the frequent consumption of soda, candy and sweets replaces the nutrient-dense foods needed to prevent such health problems.

Although Native Americans living on reservations do not have to select the heavy syrup-packed fruits, corn syrup, and honey commodities, USDA provides few alternatives. The quantity of canned fruits packed in water or juice are limited and alternatives such as fresh fruits, sugar-free gelatins, or fruited low-fat yogurts are seldom provided.<sup>55</sup>

### **Use Salt and Sodium Only in Moderation**

A frequent and excessive intake of sodium from foods or table salt increases the risk of high blood pressure, which is a common problem among certain tribal populations. Untreated hypertension can lead to heart attacks, strokes, and kidney disease.

Until recently, USDA commodities such as canned vegetables and meats, and luncheon meats contained extreme levels of sodium. Aside from these items, ingredients used in cooking or baking such as baking powder, baking soda, bouillon cubes, seasoning salts, meat tenderizers, meat sauces, catsup, mustard, relishes, and chili sauces are also major sources of sodium.

To reduce the salt and sodium content of the diet, nutritionists have instructed Native Americans to rinse canned foods well with water, reduce or eliminate the use of table salt in cooking or at the table, and reduce the consumption of purchased meats cured with salt, pickles, cheeses, prepared sauces, soups, salad dressing, and salty snacks.<sup>55</sup>

### **If You Drink Alcoholic Beverages, Do So in Moderation**

The *Dietary Guidelines* recommend that no more than one ounce of ethanol (approximately 1-2 drinks) should be consumed daily, since it is a source of calories and few vitamins or minerals.<sup>6</sup> Too often, alcohol abuse leads to crimes of violence, alcoholism, accidents, chronic disorders, and family dysfunction. Most American Indian and Alaska Native tribal communities recognize alcoholism is a serious problem and that it is related to violent behavior, accidents, and diseases of the liver. However, few are aware of its relationship to the increased risk of cancer of the pancreas, colon, stomach, kidney and breast (common cancers among American Indians or the increased risk of oral, esophageal, and larynx cancers among Alaska Natives. Cancer risk is especially high among heavy drinkers who smoke.<sup>45</sup> The rate of potential years of life lost among Native People due to alcoholism is nearly five times that of the U.S. population.<sup>64</sup>

## **EFFORTS TO IMPROVE THE HEALTH STATUS OF NATIVE AMERICANS**

The USDA and the Indian Health Service are the two Federal agencies that have the greatest influence over the health and nutritional status of Native Americans. Since their inception, these agencies have been instrumental in substantially improving the *health and well-being* of this culture. More recently, the National Heart, Lung, and Blood Institute<sup>81</sup> of NIH has provided information on how Native Americans can reduce the risk factors that contribute to their coronary heart disease; and Chapter 8 of this publication provides examples of grants and projects funded by the National Cancer Institute to reduce the cancer mortality rates of Native Americans. Provided here is an overview of efforts by the USDA and the Indian Health Service to improve the health status of Native Americans.

### **USDA Commodities**

The USDA conducts an annual survey to determine the acceptability of their commodities. In 1985, a USDA Food and Nutrition Service Task Force analyzed the FDIIR food package to determine if its contents met the nutritional needs of program participants on reservations. They concluded that with the exception of fat, the nutrient file, in general, was in compliance with the regulatory requirements. However, the USDA Task Force recommended several modifications, which have been made.<sup>56</sup>

In a 1986 Report to the USDA, Navajo Tribal Food and Nutrition Service officials commented that the commodity food package, in general, provided good food and that it



represented a better selection of food items than most people would choose on their own. The Report commented positively on the lower fat commodity chicken, tuna packed in water, unsweetened applesauce and fruit juices, light syrup packed fruits, unsalted peanuts, and the variety of complex carbohydrates provided by dried beans, grains, and vegetables.<sup>56</sup>

Although substantial improvements have been made in the nutrient content of the food package, the Navajo Tribe noted several limitations and recommendations. They requested that the USDA:

- . change the fat content of pork and beef to less than 50 and 40 percent of total calories, respectively.
- . provide chicken and turkey on a regular basis.
- . change the fat content of meatball stew to less than 35% of calories.
- . omit luncheon meats.
- . reduce the sodium content of canned meats to that of fresh meat.
- . reduce the sodium content of all canned vegetables to less than 50mg per 1/2 cup serving.

Although the USDA acknowledged the sodium levels were 5-8 times greater in some canned meats and vegetables, and 15 times greater in luncheon meats than the levels recommended by the Navajo Tribe Food and Nutrition Service officials and the American Heart Association, the USDA have not substantially lower the sodium content of their commodity foods. When further prompted with the recommendations of the 1988 Surgeon Generals' Report on Nutrition and Health, USDA commented that as new foods were added to the commodities package, the sodium, fat, and sugar contents would be evaluated and reduced *when practical and economically feasible*.<sup>56</sup>

### Nutrition in Indian Health Programs

In 1955, when the Bureau of Indian Affairs was transferred from the Department of the Interior to the Public Health Service in DHEW as the Indian Health Service (IHS), an organized department of dietary services did not exist. However, two years later a Nutrition and Dietetic Branch was created to provide therapeutic and nutrition services to Indian families. The Branch's initial focus was on feeding nutritionally adequate meals to hospital patients, and teaching families to assume responsibility for their own health by establishing sound dietary practices that included available traditional foods. Native People were also taught about food's relationship to health, growth and development.<sup>10</sup> For approximately three decades, the IHS has provided numerous comprehensive health services, including nutrition and dietetics, to American Indians and Alaska Natives living on or near federal Indian reservations or in traditional Indian territory. These efforts have resulted in a substantial decrease in infant mortality and maternal death rates, and deaths due to infectious diseases.<sup>49</sup>

In the early 1980s, the IHS shifted their nutrition priorities from malnutrition to elevating the health status of Native Americans to the highest possible level. Since 1986, their focus has been on 1) assuring the availability of high-quality, comprehensive, accessible health services; 2) providing increasing opportunities for Indians to manage and operate their own health programs; and 3) serving as advocates for Indian People. To meet these goals, 13 Native American nutritionists and dietitians, and approximately 200 Indian Health Service,



tribal, and USDA WIC nutrition professionals have attempted to incorporate nutrition education into every health, social, and education service and food assistance program available to American Indians and Alaska Natives. The objective of these professionals has been to educate Native Americans about the dietary factors associated with the chronic diseases that contribute to at least 4 of the 10 leading causes of their deaths--heart disease, cancer, cirrhosis, and diabetes--and with the prevalence of overweight, obesity, hypertension, and dental caries. A critical part of this effort has been to address the nutritional status, dietary patterns, and nutritive values of foods consumed by American Indians and Alaska Natives, and to understand better the nutrition knowledge and health attitudes of these populations.<sup>49</sup>

One significant health problem among most Indian and Alaska Native populations is obesity. A 1984 study conducted by Lee et al showed that 75% of the 1,857 American Indians representing 10 tribes in Oklahoma were obese. On the average, they weighed 145% of their ideal weight.<sup>65</sup> Accordingly, in 1990, IHS nutritionists began conducting numerous programs and activities to reduce obesity among Native Americans. These programs stress prevention rather than treatment because the former holds greater promise for long-term resolution of obesity than the latter among Native populations. The following activities were developed for family, school, and other community settings.<sup>66</sup>

#### Focus on Families

- . *Family habits:* Nutrition educators work with community volunteers, tribal program staff and IHS personnel to help families reinforce healthy habits and change risk-related behaviors (e.g., cooking techniques, exercise habits).<sup>67</sup>
- . *Adult diabetes camp:* Adult participants learn self-care skills (healthy eating, exercise, and family education) to control their diabetes. Participants are encouraged to help prevent diabetes in their own families by teaching their children and grandchildren to stay active.<sup>68</sup>
- . *Healthy children, healthy families:* Nutrition counselors use the Special Supplemental Food Program for Women, Infants, and Children (WIC) as a mechanism for teaching families about healthy lifestyle priorities.<sup>69,70</sup>

#### Focus on Schools and Youth

- . *Cooking classes:* This tribal-contracted program teaches children under age 18 how to prepare low-fat/low-sugar dishes. The meals are funded by the US Department of Agriculture.<sup>71</sup>
- . *Walking for health:* Children ages 4-10 years and parent volunteers walk one mile twice a week after school in the Fall and Spring. Before the walk, discussion are held on health and fitness topics.<sup>72</sup>
- . *Education and aerobics:* Program staff, in a school-based health program to prevent obesity, collect baseline data on body composition (including body fat distribution), fitness level, and dietary intake among Indian children grades K through 12.

Information gathered indicates a need to implement preschool and prenatal nutrition education to the numerous overweight children under age 5 years.<sup>74</sup>

*Youth health camp:* Children 9-13 years who have a family history of diabetes, heart disease, and obesity are selected to attend a youth camp. The activities during the week-long stay build self-esteem, promote healthy eating habits, and physical activity.<sup>75</sup>

### Focus on Communities

*100-mile clubs:* These exercise clubs have proven very successful in many Indian communities.<sup>76</sup>

*Nutrition education via a community supermarket:* A pilot nutrition education program was conducted in an American Indian community to assist shoppers in identifying healthier alternatives to some of their popular high-fat, high-sugar foods (e.g., whole milk, mayonnaise, sodas). The program includes recipe handouts, taste tests, in-store intercom messages, public service announcements, and billboards along the community's highways. Coordinators of this program intend to expand the program to trading posts and other local grocery stores.<sup>77</sup> A similar program in an Alaskan Native village was implemented in two local markets and the logging commissary.<sup>78</sup>

*Native American cooks:* Recognizing cooks as community leaders, IHS nutritionists conducted workshops for Native Americans who cook for hospitals, schools, and elder centers. Participants learn techniques to decrease fat and sugar, increase fiber, and control the portion sizes of high calories foods (e.g., fry bread). Emphasized are the healthy aspects of many traditional foods including wild fruits and vegetables, fish and game, beans, and corn dishes.<sup>79</sup>

### DISCUSSION

Native Americans have deep cultural and spiritual beliefs that in the past have contributed to their good health and general well-being. The restrictions and limitations placed on them by the Europeans caused major changes in their physical, mental, emotional, and spiritual well-being. Since the turn of the century when Native Americans were relegated to Federal reservations, few opportunities have been made available to them that would improve their socioeconomic and health conditions. Therefore, it is understandable why this culture has been slow to acculturate into the "white man's" society, and why they have been emphatic about retaining their traditional religious beliefs, attitudes, philosophies, and practices from generation to generation.

Attempts to improve the health and nutritional status of Native Americans living on reservations have been made by the Federal government's Department of Agriculture since the mid-1930s, and by the Indian Health Service since 1955. However, today, approximately two-thirds of this culture live off reservations and their incidence and mortality rates for most major chronic diseases continue to rise. To meet the year 2000 health objectives for Native Americans (Chapter 8) and reduce mortality rates caused by cancer and other chronic diseases, Native and non-native cultures need to cooperate. Anglo health care providers need

to be culturally sensitive to the philosophies and beliefs of Native Americans, and prevention, chronic disease risk reduction, or treatment programs must use a holistic approach that integrates Anglo measures with Native American religious, social, and health concepts to reinstate the Native individual's "balance and harmony." Moreover, Native Americans need to adhere to Anglo prevention techniques in addition to their own "cultural immunization prevention measures" to reduce their risk of chronic diseases effectively.

The Federal government needs to support a continuous monitoring system with the participation and assistance of Native American tribal councils to assess the health and nutritional status of this culture. Currently, we have gross statistics on a few tribes that are often used to estimate the extent of health problems for all Native Americans. Also, Federal agencies that provide services to this culture need funding to accommodate the health and nutritional recommendations that are known to reduce chronic disease risk factors. For example, the NCI is clear in its messages about what foods reduce the risk of certain cancers. However, due to logistical constraints, the USDA does not provide a wide variety of foods, fresh fruits and vegetables, or sufficient whole grain foods; rather, they offer items that are within their budget and that can be stored in the facilities available on reservations today. Additionally, the number of Indian Health nutrition professionals (IHS and tribal) is about one-third of the number needed to adequately provide services to the 215 reservations and the more than 500 Indian tribes, bands, pueblos, and villages. Additional nutrition professionals are needed if the year 2000 health objectives for Native Americans are to be met.

Lastly, native health professionals, tribal healers, and all Native Americans need to adhere to the traditional health and nutritional habits of their ancestors that are known to have produced balance and inner harmony. Each must take the responsibility for their path back to good health.

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## CHAPTER 8. THE YEAR 2000 HEALTH OBJECTIVES THAT PROMOTE CANCER PREVENTION AND CONTROL AMONG NATIVE AMERICANS AND THE SURVEILLANCE AND CANCER RESEARCH NEEDS TO MEET THESE OBJECTIVES

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### CHAPTER OBJECTIVES:

- PROVIDE THE YEAR 2000 HEALTH OBJECTIVES OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES, THE NATIONAL CANCER INSTITUTE, AND THE AMERICAN INDIAN TASK FORCE THAT PROMOTE CANCER PREVENTION AND CONTROL AMONG AMERICAN INDIANS AND ALASKA NATIVES.
  - PROVIDE CANCER SURVEILLANCE AND DATA NEEDS TO MEET THE YEAR 2000 OBJECTIVES AMONG NATIVE AMERICANS.
  - PROVIDE DIET AND CANCER RESEARCH NEEDS TO MEET THE YEAR 2000 OBJECTIVES AMONG NATIVE AMERICANS.
  - PROVIDE EXAMPLES OF ON-GOING ACTIVITIES BY THE NATIONAL CANCER INSTITUTE THAT FOCUS ON IMPROVING THE HEALTH STATUS OF NATIVE AMERICANS.
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### INTRODUCTION

The year 2000 health objectives from the Department of Health and Human Services (DHHS),<sup>1</sup> the National Cancer Institute (NCI),<sup>2</sup> and the American Indian Task Force (AITF)<sup>3</sup> focus on priority areas in cancer prevention and control that have the greatest potential for reducing cancer incidence, morbidity, and mortality. One important target area common to all three organizations is *dietary change*. This Chapter provides the year 2000 health objectives and the specific dietary changes in their reports that promote cancer prevention and control among Native Americans. More importantly, an overview is provided of the cancer surveillance and data research needs, and the diet and cancer research needs that are necessary to meet these health objectives. Examples of on-going NCI projects and activities that focus on the health and/or nutritional status of Native Americans are provided here and in Chapter 9-11.

## **The YEAR 2000 HEALTH OBJECTIVES THAT PROMOTE CANCER PREVENTION AND CONTROL AMONG NATIVE AMERICANS**

### **The Department of Health and Human Services**

The three major goals of the Department of Health and Human Service's (DHHS) report, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*<sup>1</sup> are: 1) *to increase the span of healthy life* of all Americans by improving the quality of life so that individuals might be vital, creative and productive; 2) *to reduce health disparities* by improving the economic and educational circumstances of the disadvantaged; and 3) *to achieve access to preventive services* by improving health through prevention. The specific objectives to reduce cancer incidence and mortality rates, and for which there is minimal or no data available on Native Americans, are:

#### **1. Cancer Health Status Objectives**

- 16.1 Reverse the rise in cancer deaths to achieve a rate of no more than 130 per 100,000 people. (Age-adjusted general population baseline: 133 per 100,000 in 1987)
- 16.2 Slow the rise in lung cancer deaths to achieve a rate of no more than 42 per 100,000 people. (Age-adjusted general population baseline: 37.9 per 100,000 in 1987)
- 16.3 Reduce breast cancer deaths to no more than 20.6 per 100,000 women. (Age-adjusted general population baseline: 22.9 per 100,000 in 1987)
- 16.4 Reduce deaths from cancer of the uterine cervix to no more than 1.3 per 100,000 women. (Age-adjusted general population baseline: 2.8 per 100,000 in 1987)
- 16.5 Reduce colorectal cancer deaths to no more than 13.2 per 100,000 people. (Age-adjusted general population baseline: 14.4 per 100,000 in 1987)

#### **2. Cancer Risk Reduction Objectives**

- 16.6 *Reduce cigarette smoking* to a prevalence of no more than 15 percent among people aged 20 and older. (General population baseline: 29% in 1987; 32% for men and 27% for women; Native American baseline: 42-70% estimated for different tribes, 1979-87.) **Specific baseline data is needed for individual Native American tribes.**

**Tobacco Objective 3.9a** reinforces the cancer risk reduction objective 16.6 by specifying American Indians and Alaska Native youths, 12-24 years reduce smokeless tobacco use to a prevalence of no more than 10 percent. (Baseline: 18-64 percent in 1987.) **Specific baseline data is needed for youths from individual Native American tribes.**

- 16.7** *Reduce dietary fat intake* to an average of 30% of calories or less and average saturated fat intake to less than 10% of calories among people 2 years and older. (General population baseline: 36% of calories from total fat and 13% from saturated fat (adults 20-74 years in 1976-80); 36% and 13% for women 19-50 years in 1985.) **No baseline data available for Native Americans.**
- 16.8** *Increase complex carbohydrates and fiber-containing foods* in the diets of adults to 5 or more daily servings for vegetables (including legumes) and fruits, and to 6 or more daily servings for grain products. (General population baseline: females: 2 1/2 servings of vegetables and fruits and 3 servings of grain products for 19-50 year olds in 1985.) **No baseline data available for men in the general population or Native Americans.**
- 16.9** Increase to at least 60 percent the proportion of people of all ages who limit sun exposure, *use sunscreens and protective clothing* when exposed to sunlight, and avoid artificial sources of ultraviolet light (e.g., sun lamps, tanning booths). **No baseline data available for general population or Native Americans.**

### **3. Cancer Services and Protection Objectives**

- 16.10** Increase to at least 75 percent the proportion of primary care providers who routinely *counsel patients about tobacco use cessation, diet modification, and cancer screening* recommendations. (General population baseline: About 52% of internists reported counseling more than 75% of their smoking patients about smoking cessation in 1986.) **No baseline data available for Native Americans.**
- 16.11** Increase to at least 80 percent the proportion of women aged 40 and older who have ever received a *clinical breast examination and a mammogram*, and to at least 60 percent those aged 50 and older who have received them within the preceding 1 to 2 years. (General population baseline: 36% of women aged 40 and older "who ever" in 1987; 25% of women aged 50 and older "within the preceding 2 years" in 1987.) **No baseline data available for Native American women.**
- 16.12** Increase to at least 95 percent the proportion of women aged 18 and older with uterine cervix who have ever received a *Pap test*, and to at least 85 percent those who received a Pap test within the preceding 1 to 3 years. (General population baseline: 88% "ever" and 75% "within the preceding 3 years" in 1987.) **No baseline data available for Native American women.**
- 16.13** Increase to at least 50% the proportion of people aged 50 and older who have received fecal *occult blood testing* within the preceding 1 to 2 years, and to at least 40 percent those who have ever received proctosigmoidoscopy. (General population baseline: 27% received fecal occult blood testing during the preceding 2 years in 1987; 25% had ever received proctosigmoidoscopy in 1987.) **No baseline data available for Native Americans.**

- 16.14 Increase to at least 40 percent the proportion of people aged 50 and older visiting a primary care provider in the preceding year who have received *oral, skin, and digital rectal examinations* during one such visit. (General population baseline: an estimated 27% received a digital rectal exam during a physician visit within the preceding year in 1987.) **No baseline data available for Native Americans.**
- 16.15 Ensure that Pap tests meet quality standards by monitoring and certifying all cytology laboratories. **No baseline data available.**
- 16.16 Ensure that mammograms meet quality standards by monitoring and certifying at least 80 percent of mammography facilities. (Baseline: an estimated 18 to 21% were certified by the American College of Radiology as of June 1990.)

In addition to these cancer prevention and control objectives, the following objectives are indirectly related to cancer prevention and control and directly related to the nutritional status of Native Americans. At present there are insufficient baseline data provided for men, women, and adolescents from *individual Native tribes* to provide insight on their status of physical activity or oral health.

#### Physical Activity and Fitness Health Status Objective

- 1.2 *Reduce overweight* to a prevalence of no more than 20 percent among people aged 20 years and no more than 15 percent among adolescents aged 12 through 19. (General population baseline: 26% for people aged 20-74 in 1976-80, 24% for men and 27% for women; 15% for adolescents aged 12-19 in 1976-90. Native American baseline: 29-75% estimated for different tribes in 1984-88.)

#### Oral Health Status Objectives

Oral cancers can be prevented since about 75 percent of these cancers are attributed to tobacco and alcohol use. Although the following objectives are not directly related to cancer, the oral health of an individual can indicate the types of foods people eat and drink and the attention paid to preventive health care.

- 13.1 *Reduce dental caries* (cavities) so that the proportion of children with one or more caries (in permanent primary teeth) is no more than 35 percent among children aged 6 through 8 and nor more than 60 percent among adolescents aged 15. (General population baseline: 53% of children aged 6-8 in 1986-87; 78% of adolescents aged 15 in 1986-87; Native American baseline: 92% for children 6-8 had cavities in primary teeth and 93% of the adolescents aged 15 had cavities in permanent teeth in 1983-84.)
- 13.5 *Reduce the prevalence of gingivitis* among people aged 35 through 44 to nor more than 30 percent. (General population baseline: 42% in 1985-86; Native American baseline: 95% in 1983-84.)

- 13.7** *Reduce deaths due to cancer of the oral cavity and pharynx of persons aged 45-74 years to no more than 10.5 per 100,000 men and 4.1 per 100,000 women. (General population baseline: 12.1 per 100,000 men and 4.1 per 100,000 women.) Specific baseline data is needed for Alaskan American tribes.*

### The National Cancer Institute

In 1971, NCI established a National Cancer Program. Since then much has been learned about the causes, treatment, and cure of the multiple forms of cancer. Armed with this knowledge, the Institute convened working groups of experts to develop quantified objectives to serve as targets for cancer prevention, screening, and treatment; and for cancer surveillance to identify measures of progress and evaluation strategies. In 1986, the NCI published their Report, *Cancer Control Objectives for the Nation: 1985-2000*.<sup>2</sup> It is a consensus statement of the NCI working groups about the potential progress American could make toward controlling cancer with the concerted efforts of public and private agencies. They suggested the following objectives:

- . *reduce the percentage of adults (from 34% to 15% or less) and youths (from 36% to 15% or less) who smoke tobacco products.*
- . *reduce the intake of dietary fat from 37-38% to 30% or less of total calories.*
- . *increase the average daily intake of dietary fiber from 8-12 grams to 20-30 grams.*
- . *increase the percentage of women, ages 50-70 years who have an annual breast screening (45%) and mammography (15%) to 80%.*
- . *increase the percentage of women, ages 20-39 years who have a PAP Smear every 3 years from 79 to 90%.*
- . *increase the percentage of women, ages 40-70 years who have a PAP Smear every 3 years from 57 to 80%.*
- . *increase the application of the state-of-the-art treatment for specific cancer sites in primary care settings.*

The Working Groups concluded that to meet these objectives by the year 2000, all Americans would have to substantially reduce their use of tobacco, consume a low-fat, high-fiber diet, participate in recommended screening measures and receive the state-of-the-art cancer treatment methods.

To achieve these goals, the NCI developed an organized network to provide information on cancer prevention, screening, and treatment to public health professionals and the public, and to provide patients with access to state-of-the-art cancer treatment. The NCI resources network includes programs that:

- . *involve community physicians* in clinical trials. (Community Clinical Oncology Programs)
- . *enhance the skills of community physicians* and other health professionals in treating cancer patients. (Cooperative Group Outreach Programs)
- . *coordinate grants for the support of projects in cancer research*, education, and control at educational and research institutions in the United States. (Cancer Center Programs)
- . *conduct clinical trials* of cancer treatment. (Clinical Cooperative Groups)
- . *provide information on cancer treatment and research protocols* designed for physicians. (A computerized information system - Physician Data Query)
- . *track cancer incidence, patient survival, and mortality* using 11 population-based cancer registries serving 12% of the nation's population. (Surveillance, Epidemiology, and End Results Program)
- . *provide immediate access to answers on cancer-related questions* from cancer patients, their families, the general public, and health professionals. (Cancer Information System)

To encourage the full use of the available cancer control measures and network resources, the NCI 1) funds basic and applied research grants in cancer prevention, screening, diagnosis, treatment, and public education; 2) provides information and technical assistance to other agencies and organizations interested in conducting cancer control activities, and 3) conducts public and professional educational programs.

### **The American Indian Task Force**

In 1987, the California Department of Health Services (CDHS) held a workshop to identify the critical health issues germane to the state's ethnic groups. The convened group concluded that while there was a large unmet need for culturally appropriate and relevant health promotion and risk reduction services, there existed a wealth of successful innovative community-based programs throughout the state. It was suggested that a forum or structure for ongoing information exchange of innovations, successful strategies, and program models specifically for health promotion be established. Since that workshop the CDHS has incorporated most of the recommendations into its state and local assistance programs by 1) *identifying health promotion priorities for their respective communities*; 2) *setting objectives*; and 3) *developing recommendations for strategies to be pursued to improve health*.

In 1990, the CDHS organized a steering committee of 15 public health leaders who represented ethnic community-based organizations, academia, and federal and county governments. This steering committee formed and provided leadership for each of the ethnic task forces. In 1991, the ethnic task forces were charged with setting health priorities, establishing objectives, and developing recommendations for four key ethnic groups: African Americans, American Indians, Asians and Pacific Islanders, and Latinos.

The American Indian Task Force (AITF) was composed of representatives from the American Indian community including researchers, academia, health care providers, and tribal leaders. This Task Force developed an American Indian Community Survey sent to Indian health clinics and various organizations and programs. Requested was input on the health promotion needs of high priority among American Indians and ethnic specific health promotion objectives for the Year 2000. Their survey showed that heart disease and stroke, cancer, diabetes, and mental health were the topic areas of high priority. Other behavioral risk factors specified included nutrition, tobacco use, and physical fitness.

In their *Report on the Year 2000 Health Promotion Objectives for American Indians* living in California,<sup>3</sup> the Task Force developed 16 objectives for cancer control which, for the most part, were in accordance with the *DHHS Healthy People 2000 Report*. However, the Task Force revised the fiber consumption objective by deleting the specific amount of grains and fresh fruits and vegetables to be consumed. Their additional objectives recommended 1) *an improved tracking system for American Indians with cancers*; 2) *that cancer registries list ethnicity*; 3) *that women's health specialists provide early detection and follow-up services*; and 4) *that low-cost services be established in isolated rural areas to provide regionalized care*.

The AI Task Force found that health issues related to nutrition and food consumption among American Indians were tightly interwoven with social, cultural, economic and physiological factors. However, they felt that because diet played an important role in the development of chronic diseases (cancer, coronary heart disease, and diabetes) and conditions (obesity, tooth decay, anemia) among American Indians, diet could also play a role in their prevention.

Using ethnic-specific data, the Task Force created risk reduction objectives in accordance with the *DHHS Healthy People 2000* objectives that address diet and physical activity. Other non-nutrition objectives were modified to address the specific needs of American Indians. Although the recommendations were directed toward persons living in California, the Task Force felt that these goals were appropriate for Native Americans living elsewhere in the United States. Table 8.1 lists the specific cancer risk reduction objectives of the American Indian Task Force and some of the projects conducted by the National Cancer Institute that coincide with the Task Force objectives.

**TABLE 8.1 RECOMMENDED NUTRITION ACTIVITIES TO REDUCE THE RISKS OF CANCER AND PROMOTE HEALTH AMONG NATIVE AMERICANS AND PROJECTS CONDUCTED BY THE NATIONAL CANCER INSTITUTE TO MEET THESE NEEDS**

THE YEAR 2000 HEALTH PROMOTION OBJECTIVES OF THE AMERICAN INDIAN TASK FORCE	ON-GOING NCI ACTIVITIES THAT REPORT FOCUS ON IMPROVING THE HEALTH STATUS OF NATIVE AMERICANS
<b>SERVICES</b>	The National Cancer Institute does not directly provide services. However, the NCI implements research and assesses the pilot studies.
<ul style="list-style-type: none"> <li>• Adapt the 1990 Dietary Guidelines for Americans to at least 80% of school lunch, breakfast services and childcare food services.</li> <li>• Increase the availability of food resources such as school lunch, WIC food supplement programs and gardening programs.</li> <li>• Increase to at least 75% the number of schools that provide nutrition education from preschool-12 grade.</li> <li>• Increase the number of sit-down and fast food restaurants that offer identifiable low-fat, low-calorie food choices.</li> </ul>	<ul style="list-style-type: none"> <li>• New Mexico's "Dietary Practices of Southwestern Indian Women" (1992-1995)</li> <li>• South Dakota's "Sioux Cancer Study" (1989-1992) [includes BRFS]</li> <li>• New Mexico's "Southwestern high Cancer Prevention Project for American Indians" (1990-1995) [grades 5 &amp; 7]</li> <li>• New York's "Reducing Cancer Risks Among Native American Youth in the Northeast" (1990-1995) [adolescents]</li> <li>• Intra-agency Agreement with the Alaska Area Indian Health Service on Risk Factors among Alaska Natives (1992-1995)</li> </ul>
<b>FOOD INTAKES</b>	
<ul style="list-style-type: none"> <li>• Reduce total fat intake to 30% of calories or less and saturated fat to less than 10% of calories among American persons ages 2 +.</li> <li>• Increase intake of complex carbohydrates (grains, fresh fruits and vegetables).</li> <li>• Increase awareness of the relationship between fat, low dietary fiber intakes and some types of cancer.</li> <li>• Reduce iron deficiency to less than 5% among children ages 1-4 and among women of child-bearing age.</li> <li>• Promote intake of calcium-rich foods 3-4 times daily among 12-24 year olds and pregnant/lactating women.</li> </ul>	



THE YEAR 2000 HEALTH PROMOTION OBJECTIVES OF THE AMERICAN INDIAN TASK FORCE	ON-GOING NCI ACTIVITIES THAT REPORT FOCUS ON IMPROVING THE HEALTH STATUS OF NATIVE AMERICANS
<b>FOOD INTAKES</b> continued <ul style="list-style-type: none"><li>● Encourage at least 50-60% of American Indian homes to prepare foods without added salt in cooking or at home table and at least 30% to purchase foods modified in sodium</li><li>● Increase to at least 50-75% the mothers who breastfeed their babies 5-6 months.</li></ul>	
<b>LIFE-STYLE</b> <ul style="list-style-type: none"><li>● Increase the % of persons who have adopted sound dietary practices and routine exercise.</li><li>● Reduce the prevalence of overweight to no more than 15% among adolescents ages 12-19 and 20% among adults ages 20 +.</li><li>● Educate at least 85% of people ages 18 + to use food labels when making food selections.</li></ul>	<ul style="list-style-type: none"><li>● New York's "Reducing Cancer Risks Among Native American Youth in the Northeast" (1990-1995)</li><li>● New Mexico's "Southwestern Cancer Prevention Project for American Indians" (1990-1995)</li></ul>
<b>RESOURCES</b> <ul style="list-style-type: none"><li>● Develop and maintain a nutritional status data base among urban and rural American Indians.</li><li>● Develop a cookbook or video that includes traditional and non-traditional recipes modified to lower fat,</li><li>● Develop culturally appropriate nutrition education materials.</li></ul>	<ul style="list-style-type: none"><li>● "Traditional Foods Can Be Healthy" Pamphlet; NIH Publication Number 93-3548. (1993)</li><li>● Ethnic and Low Literacy Diet Guide (1990-1992) [specific materials for American Indians &amp; Alaska Natives]</li><li>● New York's "Reducing Cancer Risks Among Native American Youth in the Northeast" (1989-1994)<ul style="list-style-type: none"><li>■ 3 curricula: diet &amp; nutrition; tobacco education &amp; prevention; and, a combined diet &amp; tobacco curriculum.</li><li>■ A collection of Native American Tobacco Stories</li></ul></li></ul>

**THE YEAR 2000 HEALTH PROMOTION OBJECTIVES OF  
THE AMERICAN INDIAN TASK FORCE**

**ON-GOING NCI ACTIVITIES THAT REPORT FOCUS ON IMPROVING  
THE HEALTH STATUS OF NATIVE AMERICANS**

**RESOURCES continued**

- New Mexico's "Southwestern Cancer Prevention Project for American Indians" (1989-1994)
  - "Pathways to Health" classroom curriculum, grades 5 & 7- nutrition & tobacco
  - 2-day training course, educators' training packet, 150 page teacher guide
  - "Pathways to Health Family/Community Curriculum" for American Indian families
  - "Pathways to Health School Food Service", Cancer Prevention/Health Promotion Food Service Curriculum for school food service personnel providing meals to American Indian students
  - "Pathways to Health-Life in Balance". A Cancer Prevention/Health Promotion Video tape and Discussion Guide for American Indian adults
  - Cancer Prevention/Health Promotion Food and Tobacco Pamphlets on various topics include healthful traditional American Indian foods, i.e. corn, beans, & squash; the ceremonial use of tobacco (target group: American Indian students & adults)
  - "Pathways to Health Tobacco Look-Alike" Poster for upper elementary and middle school students
  - Classroom Teaching Unit, "The Gift of Food: Native American Contributions to the World's Food" for upper elementary & middle school students

THE YEAR 2000 HEALTH PROMOTION OBJECTIVES OF THE AMERICAN INDIAN TASK FORCE	ON-GOING NCI ACTIVITIES THAT REPORT FOCUS ON IMPROVING THE HEALTH STATUS OF NATIVE AMERICANS
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RESOURCES (continued)

- Registered Dietitians/Nutritionists should be full-time staff members of Indian health clinics to provide nutrition counseling for all ages.

COMMUNITY INTERVENTION AND POLICY

- Provide low calorie meals to older Indians that are low salt low cholesterol.
- Fund food preparation demonstrations using traditional native foods.
- Encourage the Indian Health Service clinics & programs to cosponsor & promote activities that encourage tribal & urban Indian participation.

- The *Network for Cancer Control Research among American Indian and Alaska Native Populations* includes actions items which relate to objective in the "National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives"

- New York's "Reducing Cancer Risks Among Native American Youth in the Northeast"(1990-1995)
  - Educator training (all are American Indian or Alaskan Natives); 18 tribal communities involved; 2 control sites & 6 intervention sites; traditional stories & crafts; elders participate in after school activities.

- New Mexico's "Southwestern Cancer Prevention Project for American Indians" (1990-1995)
  - 15 schools in 12 different areas; 4 areas are controls & 8 are intervention sites; 2-day educator training workshops; elders from local tribal communities participate in the teaching.

- The *Network for Cancer Control Research among American Indian and Alaska Native Populations* includes actions items which relate to objective in the "National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives"
- The Science Enrichment Program (1992-1995)

- Direct funding to programs educating American Indians about dietary choices to prevent & control certain chronic diseases & the importance of routine exercise.

Currently, there is *insufficient information about the health and nutritional status of specific tribes of American Indians and Alaska Natives* to assess the extent to which the aforementioned health objectives need to be met. To represent their cancer prevention and control needs adequately, these populations need to be surveyed systematically and monitored over time. There are 512 federally recognized tribes of Native Americans. While there are some similarities among all 512, each tribe has its own idiosyncracies which makes it unique and may provide reasons why some tribes have higher incidence and mortality rates for chronic diseases than others. Therefore, it would be important to collect data from all tribes with ample sample sizes to assess health and nutritional status; to collect this information from a few tribes and assume that it apply to all tribes is erroneous.

In the past, the major reasons for not surveying Native Americans may have been due to the logistical problems involved with data collection. For numerous reasons, Native Americans are apprehensive when non-Native people come to their homes for the sole purpose of assessment and intervention. However, there have been successful research projects conducted by non-Native Americans with the assistance of the tribal council and community members, and a survey modeled on the NHANES that was conducted on and near the Navajo Reservation (Appendix F, Section II). There are also cancer prevention and control interventions in progress that involve non-Native and Native American lay-people and researchers (Table 8.1).

Non-Native investigators need to be aware of the diverse variety of health, nutritional, socioeconomic, geographical, and cultural issues that confront different tribal communities. And, it is imperative that researchers solicit the assistance of tribal councils and the participation of Native People when developing strategies to improve the health and nutritional status of a tribal community. Health promotion programs must be culturally and linguistically appropriate for each tribal community because mainstream health education activities often are not appropriate or meaningful to these populations.<sup>4</sup> The following section describes what types of cancer surveillance and nutrition research needs must be met to adequately meet the cancer prevention and control needs of American Indians and Alaska Natives.

## **SURVEILLANCE AND CANCER DATA NEEDS**

Until 1990, the National Nutrition Monitoring System (NNMS) was used in the United States to provide timely detection and measurement of the nutritional problems, dietary practices, and nutrition-related knowledge and behaviors of the general population and of specific high-risk groups. Surveillance of the food and nutrient intakes and the nutritional status of Americans were periodically surveyed by the U.S. Department of Health and Human Services (DHHS) and the U.S. Department of Agriculture (USDA). The DHHS was the primary collection agency for health information and the USDA was responsible for analyzing the nutrient contents of foods and monitoring the food supply. All of these data are necessary when studying the relationships between diet and chronic diseases.<sup>5</sup>

Today, the NNMS has been replaced by the *National Nutrition Monitoring and Related Research Program* (NNMRRP) which is jointly conducted by the DHHS and the

USDA. In 1990, the National Nutrition Monitoring and Related Research Act required that these two Federal agencies establish and implement a ten-year comprehensive plan that would complement and enhance the wide range of nutrition monitoring activities that have been underway for many years. In the June 1993 issue of the Federal Register, the DHHS and USDA announced the issuance of their *Ten-Year Comprehensive Plan for the National Nutrition Monitoring and Related Research Program*. Several of the following suggestions made by the public were incorporated into the plan prior to its release. The issues raised were 1) for an improved and timely dissemination of data and information from the Program; 2) organizational accountability for each activity; 3) specific description of how population subgroups at nutritional risk would be addressed; 4) inexpensive methods for assessing the nutritional status of populations at State and local levels; 5) recognizing the importance of surveying food availability throughout the Nutrition Monitoring Program; 6) including brand name data in the food and nutrient data base; and 7) using food intake surveys to estimate exposure and risk for environmental contaminants and pesticide residues.<sup>6</sup>

One of the planned activities in the *Ten-Year Comprehensive Plan* is to develop and implement a plan for improved coverage of subgroups of the population at nutritional risk, e.g., American Indians and Alaska Natives. This coverage would include a compilation of existing surveys, surveillances, and related research information; the assessment of gaps in information and recommendations for technical and research related assistance to Federal, State, and local jurisdictions to improve their coverage of selected subgroups. As part of the NNMRRP, the Indian Health Service conducted the Navajo Health and Nutrition Survey during 1991-92.<sup>6</sup>

Much of what the NNMRRP has planned coincides with the *Healthy People 2000 Report*<sup>1</sup> recommendations, e.g., data collection and assessment of the nutritional status of Native Americans on reservations, and the development of survey methodologies specific to population groups that would provide baseline information for studying the relationships between diet and chronic diseases. The *Health People Report* also emphasized the need for smaller, definitive sets of indicators that would help to facilitate comparisons of health status between similar and different populations (or tribes). Achieving the following objectives would provide the types of information that currently do not exist for all major American Indian and Alaska Native tribes or update older studies of these tribes.

The following research needs as specified in the *Healthy People 2000 Report* have been modified slightly for Native Americans and are divided into three categories: general surveillance and data systems needs, cancer surveillance needs, and high priority cancer control and cancer prevention research needs. This section is followed by a detailed description of nutrition and cancer research needs that will benefit the general population including Native Americans.

### **Surveillance and Data Systems Needs**

*Develop a set of health status indicators appropriate for American Indians and Alaska Natives that can be used by Federal, State, and local health agencies, and Indian clinics.*

- . *Identify, and create tribal data sources* to measure progress toward each of the year 2000 national health objectives specific to Native Americans.
- . *Develop and disseminate procedures for collecting comparable data* from the various Native American Indian tribes and Alaska Native tribes for each of the year 2000 national health objectives for incorporation into the Indian Health Service and/or a Public Health Service data collection system.
- . *Develop and implement a national tribal process to identify significant gaps* in disease prevention and health promotion data among specific American Indian and Alaska Native tribes.

#### **Cancer Surveillance Needs**

- . *an expansion of surveillance resources* to provide both a more nationally representative and epidemiologically diverse data base on cancer risk, incidence, and survival *American Indians and Alaska Native* children, adolescents, and older adults.
- . *an expansion of population-based cancer registries and reporting systems* to provide national, State, and local information on cancer incidence and survival rates of Native Americans. Data should be comparable across registries and compatible with NCI's Data, Epidemiology, and Results Program (SEER), and include smoking, occupation, and treatment data.
- . *collection of periodic data on the cancer-related knowledge, attitudes, and behavior* of the general population with oversampling of American Indians and Alaska Natives and other low income, low-education populations.
- . *periodic surveys of primary care providers to monitor the training and behavior of practicing clinicians* regarding tobacco use cessation and screening for early detection of cancer and to provide national estimates across professional groups and specialty areas.
- . *surveillance of dietary fiber intake* of the population utilizing the information on 400 foods analyzed by the National Cancer Institute for total dietary fiber, soluble fiber, insoluble fiber, lignin, cellulose, hemicellulose, and pectin.

According to the *Healthy People 2000 Report*, the potential for reducing cancer incidence and mortality rates through prevention and early detection and control appears to be large. Collectively, the previous and following objectives, which have been modified slightly for Native Americans, have the greatest potential for expanding and coordinating efforts to effectively apply current information and strategies to reduce the cancer incidence and mortality rates in the coming decades.

**High priority Cancer Control Research Needs include:**

- . *determining the behavioral and environmental determinants of cancer (e.g., socioeconomic, ethnic, cultural).*
- . *determining the effective channels and techniques for cancer prevention and control for use by health care professionals, schools, mass media, public health departments, community coalitions, marketing channels, and networks.*
- . *determining what initiates tobacco use in youth and developing effective interventions to prevent early use of tobacco.*
- . *developing and testing cancer prevention and control interventions that are appropriate for specific American Indian tribes and Alaskan tribes.*
- . *determining the implications of interventions for the Native American public, professionals, and society.*
- . *determining if and why cancer incidence and death rates differ with advancing age among Native Americans.*
- . *determining ways of improving access to the state-of-the-art cancer screening and care.*
- . *determining why different cancer mortality rates exist among American Indian and Alaska Native tribes and ways to reduce all cancer mortality rates.*
- . *determining which early detection tests are effective for specific age and risk groups.*
- . *determining which methods of early detection services are most cost-effective.*
- . *developing new early detection technology (e.g., blood serum markers, that are applicable to American Indians and Alaska Natives.)*
- . *developing new statistical methods to evaluate screening in controlled and uncontrolled trial settings.*
- . *developing ways to improve the quality of early detection and screening services.*

**High priority Cancer Prevention Research Needs include:**

- . *determining what role dietary components, such as fiber, play in the relationship between food intake, biochemical levels of nutritional compounds, and cancer incidence of American Indians and/or Alaska Natives.*

- . *determining the relative importance of cancer risk factors* and the temporal relationships between risk factor reduction, cancer incidence, cancer survival, and cancer mortality.
- . *determining the efficacy* of potential chemopreventive agents.
- . *identifying foods, dietary factors, and herbs* (and their underlying mechanisms) that alter risks for specific cancers among Native Americans.
- . *quantifying the dietary macro- and micro constituents* associated with cancer prevention among Native Americans.
- . *expanding and improving computerized simulation models* of temporal paths of cancer incidence, survival, and mortality.
- . *developing a reliable data base* of the economic costs of cancer and its treatment among Native Americans.
- . *determining the economic and organizational aspects* of cancer prevention and control services among Native Americans.
- . *developing effective ways of distributing research* on the effective channels and techniques for cancer prevention and control interventions to primary care providers and other users of this information.
- . *developing effective ways of distributing information* about the determinants of tobacco use in Native American youth and effective interventions to prevent early initiation of tobacco use.
- . *developing effective ways of distributing research results* on cancer prevention and control interventions to Native American professionals and lay-Native Americans.

### **Nutrition and Cancer Research Needs**

Aside from the fundamental cancer surveillance and data research needs, there are significant nutrition concerns for which national population data are currently unavailable. For example, there is a dearth of information on the consumption practices of Native Americans living among the general population, and very few tribe specific studies that provide this information on those who live on reservations. Therefore, to address cancer prevention among this culture adequately, data are needed on their health, dietary and nutritional status. In addition, there are nutrition and cancer research needs that must also be met to address the cancer prevention and control needs of this culture and all Americans. According to the Reports of the Department of Health and Human Services<sup>1</sup> and/or the National Academy of Sciences<sup>7</sup>, research is needed to determine:

- 1 *the role of specific dietary factors in the etiology and prevention chronic diseases, including cancer.*<sup>1</sup> Although many dietary constituents are already known to play a role in the etiology of chronic diseases, specific knowledge about the mechanisms



of action will lead to definite conclusions and provide more precise guidance about how to reduce the risk of different chronic diseases. Specific research is needed to determine the<sup>7</sup>:

- . effects of energy intake per se from those of specific sources of calories, e.g., fats on disease risk, especially the risk of certain cancers, obesity, and non-insulin-dependent diabetes mellitus.
- . mechanism of the type of dietary fat that influences different stages of carcinogenesis, e.g., polyunsaturated fatty acids (PUFA - omega-3 and omega-6) and cancer risk, or monounsaturated fatty acids (MUFA) intake and breast cancer risk.
- . relative importance of different types of proteins (animal and vegetable) compared to different types and amounts of fats in chronic disease etiology and their mechanisms of action (e.g., different cancers, coronary heart disease (CHD), hypertension, and stroke).
- . relative effects of different types and amounts of fibers in chronic disease etiology and the mechanisms whereby they may affect different cancers, serum lipid levels, CHD, diabetes and gallstones.
- . nutritional, environmental, behavioral and genetic factors in the etiology of obesity associated with chronic diseases.
- . link between the intake of total carbohydrates, different types of carbohydrates, and stomach cancer.
- . mechanisms whereby chronic alcohol ingestion increases the risk of hypertension and possibly that of breast cancer.
- . further identification of the constituents in plant foods (vegetables, whole-grain products, and citrus fruits) that may modify the risk of different chronic diseases and clarify their mechanisms of action.
- . specific dietary and environmental factors associated with vegetarian lifestyles and their relative contribution to the overall maintenance of health and reduction of the risk of specific chronic diseases.
- . potential role of specific B vitamins in carcinogenesis and of carotenoids as potential chemopreventive agents for specific neoplasms.
- . mechanisms whereby vitamin E deficiency combined with a high PUFA intake may enhance carcinogenesis.
- . mechanisms, other than nitrosamine-inhibition, whereby vitamin C may influence carcinogenesis and the specific effects of vitamin C versus those of other substances in plant foods that are associated with a lower cancer risk.

- . relative role of different types of coffee and constituents of coffee and tea in altering cancer risk and in affecting serum cholesterol levels and heart disease risk.
- . carcinogenic potential of suspect carcinogens in common foods, e.g., certain mycotoxins, polycyclic aromatic hydrocarbons, and naturally occurring constituents such as flavonoids.
- . effect of diet on the endogenous formation of mutagens, such as nitrosamines and fecal and urinary mutagens, and the carcinogenicity of such mutagens.

2 According to the *Diet and Health Report* there is a strong need to quantify the adverse and beneficial effects of diet and determine the optimal ranges of intake of dietary macro- and micronutrients that affect the risk of chronic diseases. Specific research is needed to determine the<sup>7</sup>:

- . effect of the type and amount of fat and the risk of breast, colon, and prostate cancers, and cardiovascular disease.
- . levels of fat intake associated with the maximum risk reduction for cancer.
- . effects of very high intakes of PUFA (e.g. the kind found in fish oils) on cancer and cardiovascular disease risks
- . optimal range of protein intake by identifying the effects of the amounts and types of protein on certain cancers.
- . nature of the interaction between protein and different carcinogens in experimentally induced carcinogenesis.
- . long-term effects of increasing the complex carbohydrates (starches and fibers) in the diet of persons with stomach or pancreatic cancers, or diabetes. Specify roles of individuals fibers at disease onset.
- . optimal range of intake of water-soluble vitamins for prevention of chronic diseases, especially cancer and liver disease at all stages of the life cycle.
- . interactions among nutrients alone or with other environmental risk factors at ranges of exposure that have the potential for modifying chronic disease risk. For example, the interactions:
  - of physical activity, fat intake, and obesity;
  - alcohol and vitamin A or alcohol and the B vitamins and cancer;
  - fiber and micronutrients such as calcium, zinc or vitamin C and cancer or other chronic diseases;
  - vitamin E, selenium, and cancer;

- synergistic and antagonistic interactions among food additives, contaminants, nutrients, and cancer risk.

**3** According to the *Diet and Health Report*, there is a need for improved methods to collect information from population subgroups to assess how the foods and dietary constituents they eat may be used to alter the risk of chronic diseases. Methodological shortcomings of survey data often limit precise conclusions about the associations of diet and chronic diseases and it has been recommended that better methods be developed<sup>7</sup>:

- . to monitor and quantify the nutritive and nonnutritive substances in foods consumed by humans.
- . to monitor frequent and long-term dietary intake of populations.
- . to quantify dietary intake, especially for energy and alcohol.
- . for data analysis of epidemiologic studies (e.g., using statistical methods that account for collinearity and multiple interactions among dietary variables, and that permit simultaneous analysis of the association between specific foods, food classes, and food constituents, and disease end points.

**4** *biochemical markers of dietary intake to improve ability to monitor the effects of dietary interventions.*<sup>1</sup> According to the *Diet and Health Report*, "biochemical markers" are needed to circumvent the shortcomings of using the disease itself as the sole end point, and to circumvent the problem of misclassifications from dietary recalls. The *Report* also points out that both "markers of exposure" and "early indicators of risk" are needed to forecast the emergence of clinical disease, and that genetic markers can identify high-risk subgroups in the population. "Marker" and other research are needed to determine<sup>7</sup>:

- . better biochemical markers of exposure to dietary fats and early biological markers of neoplasia.
- . genetic control of response to dietary fats, the interactions of genetic factors and dietary fats, and their impact on specific chronic diseases, especially cancer, gallbladder disease, and cardiovascular diseases.
- . the role of gene-nutrient interactions in the etiology of certain cancers, diabetes, food intake and obesity, alcohol dependency, hypertension, dental caries, and osteoporosis.
- . simpler methods for identifying high-risk groups.

- 5 *effective educational methods to translate dietary recommendations into appropriate food choices and sustained behavioral changes for various population groups.*<sup>1</sup> Similarly, the *Diet and Health Report*, stresses the importance of intervention studies to assess the impact of dietary recommendations among population groups. Any intervention study should be accompanied by effective monitoring to assess disease incidence, prevalence, and mortality rates.<sup>7</sup> No study has translated NCI dietary recommendations into appropriate food choices for the various American Indian or Alaska Native tribes and evaluated the long-term impact.
- 6 *food labels that are more informative and useful to the public.*<sup>1</sup> The content and format of food labels have changed since this research recommendation was written. Efforts now are needed to teach people what these labels mean and how to use them. The *Diet and Health Report* also recommends that social and behavioral research be conducted to better understand the factors that motivate people to modify their food habits. This knowledge is necessary for designing *effective* public health programs to reduce the risk of chronic diseases. Specific research is needed:<sup>7</sup>
- . to compare the behavior and motivations of people who have changed their food habits with those who have not.
  - . to monitor factors present at the time of changes in eating habits.
  - . on methods of reducing obesity and maintaining weight loss.
  - . on methods for controlling alcohol abuse and alcohol dependency.
  - . on methods of monitoring and evaluating the impact of dietary recommendation (e.g. guidelines) on chronic disease risk.
  - . on ethnic and cultural differences in response to dietary modification and the means of incorporating these differences in strategies for risk reduction.

Currently, some national data files are too large and complex for the average user, while others important files are not available for public use. An effective cancer and nutrition research data base should consist of small files that are user-friendly, accessible, and cost- and time-effective. Proper documentation should state what the data limitations are and where they occur in the data set. It is also recommended that the information be made available at national, State, and local levels.

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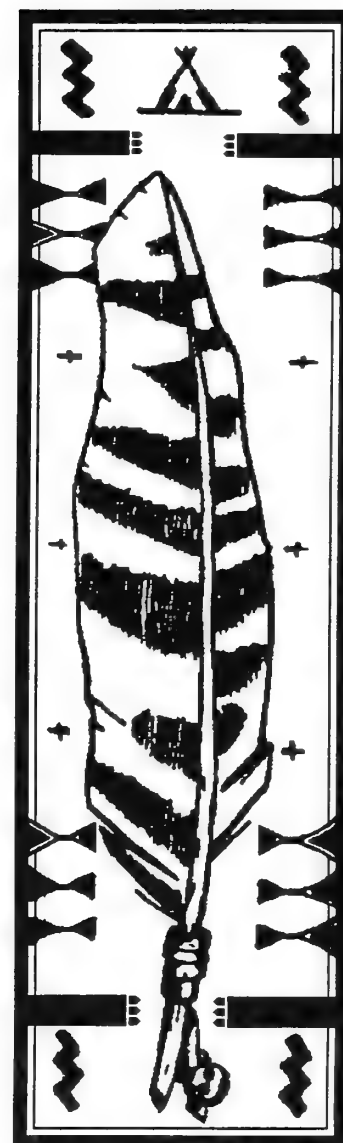
# SECTION III

## NCI NATIVE AMERICAN PROJECTS AND ACTIVITIES

The *Healthy People 2000* objectives include "reverse the rise in cancer deaths to achieve a rate of no more than 130 per 100,000 people (age-adjusted baseline: 133 per 100,000 in 1987)." The National Cancer Program is designed to encourage consortia of existing cancer control-related research institutions and relevant regional health agencies to pool their resources and conduct cancer control research projects directed towards achieving that goal. To have the maximum impact on achieving the year 2000 goals, specific emphasis has been placed on developing programs that address the specific cancer control problems of high-risk and hard-to-reach populations and on establishing an effective linkage with regional health agencies to foster appropriate technology transfer/cancer control applications. In accordance with the National Cancer Program's goal to address the cancer needs of all United States citizens, NCI has initiated a program which addresses cancer prevention and control needs for special populations. These special populations include American Indians and Alaska Natives.

The National Cancer Institute (NCI) is the Federal Government's principal agency for conducting and supporting research on cancer and is responsible for overseeing implementation of the National Cancer Act which coordinates a national research effort on cancer cause, prevention, detection, diagnosis, treatment, rehabilitation and control. The Division of Cancer Prevention and Control, Special Populations Studies Branch (SPSB) of NCI is designed to address NCI's year 2000 goals to reduce and eliminate the differentials in cancer incidence, mortality and survival between minority/special populations and the general population. The terms "special populations" includes Alaska Natives and American Indians among other populations who are known to experience high cancer rates.

The projects which are briefly described within this Section illustrate the diversity of NCI's Native American Initiatives. The projects are designed reduce the barriers to cancer screening and early detection and to provide improved data on American Indian and Alaska Native People's cancer incidence, mortality, and survival. The NCI acknowledges that further development, implementation, and evaluation are necessary to continue these efforts to meet the cancer prevention and control needs of American Indians and Alaska Natives.







## CHAPTER 9: SPECIAL POPULATIONS STUDIES BRANCH NATIVE AMERICAN COOPERATIVE AGREEMENTS

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### CHAPTER OBJECTIVES:

- DESCRIBE NATIONAL CANCER INSTITUTE'S SPECIAL POPULATIONS STUDIES BRANCH  
NATIVE AMERICAN COOPERATIVE AGREEMENT RESEARCH PROJECTS.
    - ◆ STUDY COMPONENTS
    - ◆ COLLABORATIVE RESEARCH ACTIVITIES
    - ◆ INTERVENTION PRODUCTS
- 

### INTRODUCTION

This chapter describes the eight Native American cooperative agreements. Native American researchers who are interested in pursuing projects with the NCI have frequently requested clarification regarding NCI-supported research in comparison to research supported by other funding sources. The Native American cooperative agreements are described in depth to illustrate the depth and breadth of work which is implemented under a cooperative agreement mechanism.

### Overview of the Special Populations Studies Branch

**Rationale:** The development of a cancer prevention and control research base with a primary focus on minority and underserved populations will enhance the delivery of interventions that focus on the unique needs of these groups.

The Special Populations Studies Branch (SPSB) supports programs targeting populations at high risk for cancer incidence and mortality rates. These programs include extramural intervention research projects as well as initiatives that provide rapid response to an identified need or a request for action. For example, the SPSB has funded seven research studies to develop and test innovative cancer control interventions among minority and underserved populations. The SPSB also is supporting studies addressing the identification and remedy of key factors that contribute to avoidable cancer mortality among Blacks and other minority populations. Intra-agency activities with the Indian Health Service and Health Resources Services Administration include initiatives concerning the cancer surveillance of Alaska Natives and the delivery of cancer control services to community and migrant health centers, respectively.

The SPSB also focuses on identifying collecting, analyzing, and disseminating data on the cancer prevention and control needs of special populations. To augment Surveillance, Epidemiology, and End Results (SEER) Program data on certain racial and ethnic populations, the SPSB is pursuing the inclusion of data obtained from additional registries that are located in geographical areas where SEER representation is low. In addition, the SPSB is collaborating with Federal, State, and local agencies to produce the population estimates needed to evaluate cancer risks among special populations.

### **Cooperative Agreements**

A Cooperative Agreement, or "U01" is a funding mechanism which is used where an assistance relationship exists between the NCI and the grant recipients. Through this mechanism, NCI is allowed to provide substantial programmatic involvement as well as provide technical assistance to the grant recipient. The NCI assists, supports or stimulates and participates substantially with recipients during the performance of the contemplated research activity. The following cooperative agreements include collaboration among the projects as well as with NCI staff.

The Special Population Studies Branch, CCSP, DCPC, NCI released two requests for applications (RFA) in 1989 focusing on intervention research in Native American populations; one on "Avoidable Mortality from Cancers in Native American Populations" (cervical and breast cancer) and the other on "Primary Prevention of Cancer in Native American Populations" (tobacco use and diet). Eight projects were awarded during the Spring and Summer 1990 as five year cooperative agreements with the NCI. Four projects were avoidable mortality and four were primary prevention.

## **ORGANIZATIONAL FUNCTIONING OF THE COOPERATIVE AGREEMENTS**

### **Meetings**

The Avoidable Mortality Steering Committee is comprised of the principal investigators and approximately two to three selected members of their research team as well as the NCI Native American program director. Likewise, the Primary Prevention Steering Committee includes the principal investigators and approximately two to three selected members of their research team and the NCI program director. The chair of the Steering Committee is a principal investigator and serves for one year. The Cooperative Agreement Steering Committee is comprised of both groups. The Cooperative Agreement Steering Committee meets together as a group once each year in Rockville, Maryland. The Avoidable Mortality Steering Committee and the Primary Prevention Steering Committee hold separate semi-annual meetings. Each meeting is two to three days in length. Meeting agenda topics are a culmination of discussion between principal investigators and the NCI Native American program director.

### **Conference Calls**

The Avoidable Mortality Steering Committee has a conference call the first Thursday of approximately ten months of the year at 3:00 p.m. Eastern Time. The Primary Prevention Steering Committee has a conference call every other month on the first Friday of the month at 12:00 p.m. Eastern Time.

## **Publication Guidelines**

Due to the numerous problems which have occurred among Native people in the past regarding research and publishing of research findings of Native peoples, the SPSB initiated discussions to develop mutually comfortable publication guidelines among the research team and Native communities. The intent of discussing publication guidelines is to create rapport of trust and collaboration on the project, to increase the likelihood of Native peoples having access to research findings and to allow for Native Peoples' input into the types of statements which are made about one's local Native community, and to provide opportunities/promote Native American authorship of publications.

## **AVOIDABLE MORTALITY FROM CANCERS IN NATIVE AMERICAN POPULATIONS**

### **Program Goal**

The goal of NCI's "Avoidable Mortality from Cancers in Native American Populations" Program was to identify key factors that contribute to avoidable mortality from specific cancers such as cervical and breast cancer; develop and evaluate the effectiveness of community baseline interventions; and reduce mortality from specific cancers (e.g., cervical, breast). The four projects focused on Native American communities: one targeted American Indians in the Southeast; one focused on urban Indians in seven geographically diverse settings; one targeted rural Native Hawaiians; and one focused on Alaska Natives in an urban setting and a rural setting. Knowledge, attitudes, and screening practices were addressed. All were random trials and all involved interventions.

### **1. Bowman Gray North Carolina Project**

The "Prevention of Cervical Cancer in Native American Women" in North Carolina, focused on women from the Lumbee Tribe and the Eastern Band Cherokee Tribe. The Cherokee are a reservation tribe residing in the western-most region of North Carolina. Women from each tribe were randomly divided into intervention and control groups after recruitment. The purpose of the project was to prevent cervical cancer by increasing the proportion of women who received regular Pap smears and return for follow-up care when necessary. Women age 18 and older who were enrolled members of the Cherokee and Lumbee tribes were eligible for inclusion in the project. The Cherokee study population included all women age 18 and older residing on the reservation in western North Carolina. The Lumbee study population was randomly selected from female tribe members who were residents of Robeson County, North Carolina (the traditional homeland of the tribe).

Project goals were to be obtained by development and implementation of a focused, culturally sensitive, community health education intervention. Supported by extensive community analysis, the intervention was presented to women individually by trained Native American lay health educators. The intervention included an initial presentation of information about cervical cancer and its prevention. Information presented was reinforced and augmented in subsequent contact with participants through mail and telephone.

A total of 1000 eligible women were recruited in each population. These women were randomly assigned to one of four groups of 250. Using the Solomon Four Group design, 500 of the women in each population (two groups) received the pretest interview. One of these groups received the intervention. One of the remaining two groups that were not interviewed

also received the intervention. This design was selected because it allowed estimation of the effect of the pretest interview as an intervention. All women are to be interviewed after the intervention. Outcome measures include changes in knowledge, attitudes and behaviors with regard to cervical cancer and early detection. Data on Pap smears were also collected from medical providers servicing each population. These data were to be used to evaluate the accuracy of responses on the pretest interviews.

## **2. The American Indian Health Care Association Project**

The "Urban Native American Women's Cancer Prevention Project" focuses on Native American women age 18 and over from seven urban areas at seven urban Indian Health Centers and a clinic-based patient outreach to urban Native American women in four intervention communities. The project sites include clinics and Indian Health Boards in Seattle, Salt Lake City, Oklahoma City, Tulsa, Detroit, Milwaukee, St. Paul, and Minneapolis. The purpose of the project is to: 1) assess cancer prevention knowledge, attitudes, and behaviors; 2) develop culturally-sensitive prevention intervention strategies; and 3) evaluate the effectiveness and efficacy of those strategies.

Both Primary and secondary prevention intervention will be provided through four well-established urban Native American health programs, with three other matched clinic settings serving as comparison sites. The intervention will consist of 1) a review of patient records to determine the proportion of eligible women who are receiving annual Pap smear examinations and subsequent contact of eligible non-screened clients by field workers to induce their participation; 2) educational outreach into the community by trained Indian health community health workers for primary prevention 3) cancer education programs provided by health professionals for women who come into the clinic for screening, 4) health provider training for Indian nurse educators on clinical cancer prevention, and for non-Indian community health organizations on providing culturally sensitive treatment to urban Indian women; and 5) case management services for women patients to assess their options for health care services and reduce financial barriers to follow-up care.

Evaluation of the study will be accomplished by measuring the number of participants who are screened, as well as those who receive follow-up treatment.

## **3. The Wai'anae Coast Cancer Control Project**

The "The Wai'anae Coast Cancer Control Project" targets Native Hawaiian women 18 years of age and older. The purpose of the project is to test the effectiveness of an integrated, community-driven cancer control intervention to increase breast and cervical cancer screening rates as well as increase knowledge, attitudes, and behavior (KAB) scores among participants. The primary intervention is the development of health-activated mutual support groups ("Kokua Groups") within existing Hawaiian social networks.

This project will test the effectiveness of an integrated, community-driven cancer control intervention which has been designed to take advantage of Native Hawaiian social and family networks and their sense of "Kokua" a Hawaiian social concept that encourages mutual support of community members. "Kokua" groups will be formed to provide linkage between health workers and native Hawaiian women and to encourage mutual-support in addressing cancer issues among community members. Project effectiveness will be measured by changes in mammography and PAP screening rates and in increased knowledge, attitudes, and

practices (KAP) scores among Kokua group members (n=1400). Process evaluation will determine project components which were influential in affecting screening rates. Community diffusion will be assessed by telephone surveys of an empaneled random sample of community members (n=600). KAP changes among this telephone survey sample will be compared to a telephone survey of Native Hawaiian women outside the intervention area (n=600 empaneled). An additional group of 600 women in both populations will be surveyed to control for the "learning" effect of participating in telephone surveys.

#### **4. Alaska Area Native Health Service and Aleutian/Pribilof Islands Association, Inc.**



The project "Prevention of Cervical Cancer in Alaska Native Women" targets Alaska Native women age 18 and over in two locations; one urban area--Anchorage, at the Alaska Native Medical Center and one rural area--St. Paul Island, in the Pribilof Islands. In Anchorage, 500 women will be enrolled from a random sample of the 5000 eligible Native residents of the area. In St. Paul, all adult women (approximately 125) are eligible to participate.

The long-term objectives of this project are to reduce the morbidity and mortality from invasive cervical cancer in Alaska Native women. The specific aims are: to promote knowledge and awareness of this disease, its risk factors and appropriate screening programs; and to enhance the existing cervical cancer screening services and follow-up care of precancerous lesions.

Participants agree to complete face-to-face interviews, pre- and post-intervention, focusing on their knowledge, attitudes and behaviors with regard to cancer in general and cervical cancer in particular. Review of medical charts and records from cytopathology labs provide documentation of actual pap smear screening activity.

Intervention strategies will be implemented following enrollment in the project. One intervention is a special demonstration women's health clinic. This Women's clinic includes: extended evening hours, hour-long appointments, staffing by women providers and nurse practitioners, comprehensive health surveillance for women of all ages, pap tracking services, individual patient education, mammography services, and tobacco cessation classes.

Outcome measures include: annual screening rates for women in the project compared with non-participants, rates of completion of scheduled appointments, and the time interval from the receipt of abnormal pap smear results, to the initiation and completion of follow-up treatment.

**Table 9.1 Study Components of Avoidable Mortality from Cancer in Native American Populations Projects in Alaska, Minnesota, North Carolina, and Hawaii.**

Study Components	Alaska	Minnesota	North Carolina	Hawaii
Target Population	Alaska Native Women, Age $\geq 18$	Native American Women Age 18 +	Native American Women Age 18 +	Native Hawaiian Women Age 19 +
Subjects	Stratified random sample from IHS medical service recipients	First 160 patients from each clinic	Random samples from Lumbee tribal rolls, area sample of Cherokee reservation	Random generated telephone numbers in selected census tracts
Sample Size	500 from Anchorage, 125 from St. Paul	160 patients from each clinic	1000 from Lumbee and Cherokee tribes	1200 baseline control, 1400 full-scale intervention
Sites	Urban and rural communities in Alaska, Anchorage and St. Paul Island	7 sites, 3 matched pairs plus one addition	Lumbee and Cherokee populations. Each population managed as separate experiment	Experimental group selected from Wai'anæ Coast. Control selected Native Hawaiian population on Oahu

## PRIMARY PREVENTION OF CANCER IN NATIVE AMERICAN POPULATIONS

### Program Goal

The goal of this initiative is to develop innovative tobacco and/or dietary intervention programs and determine the long-term effectiveness of these programs on the prevention of cancer among Native Americans. These projects are developing a variety of techniques to prevent or reduce habitual tobacco use (NOTE: the projects are distinguishing between Native American ceremonial tobacco use and habitual use). Two projects target school age American Indian children and stress dietary modification and prevention of habitual tobacco use. Another project targets American Indian adult tobacco cessation and the fourth is working with tribal councils on developing tobacco use policies. The settings include urban clinics, rural settings, and reservations. Knowledge, attitudes, and practices are also being addressed. All four of the funded projects focus on American Indians.

## 1. The University of New Mexico's Project

The University of New Mexico's, "Southwestern Cancer Prevention Project for American Indians" is targeted to 500 Southwestern Indian children in grades five and seven (primarily Navajo and Pueblo Indians). The project includes New Mexico sites: Alamo, Santa Fe, Crownpoint, San Juan, Laguna-Acoma, Thoreau, Borrego Pass, Espanola, Smith Lake; Utah site: Aneth; and Arizona sites: Hopi and Keams Canyon. The first goal of this multidisciplinary research project is to prevent smoking and the use of smokeless tobacco among Southwestern Indian school children. The second goal of the study is to promote dietary intake of less fat and more fiber. The experimental design includes a comparison of the effectiveness of the "Pathways to Health" curriculum toward change in health knowledge, attitudes, and behaviors: 1) as taught in fifth and seventh grades, 2) when augmented with a family/community intervention, and 3) with a control curriculum (solvent abuse prevention). Physical measurements (height, weight, and skinfolds) as well as other demographic and normative data are also being collected.

The researchers are developing, implementing, and evaluating a curriculum that focuses on avoiding tobacco use and promoting a healthful diet, using methods derived from social learning theory, developmental theory, and good education practices. They are also employing culturally relevant approaches to instruction. For example, a distinction is being made between traditional ceremonial tobacco use versus indiscriminate abuse. Indian contributions to American agriculture and diet are being integrated in the curriculum as well. Indian educators, health educators, and nutritionists are a part of the team that is planning, implementing, and evaluating the curriculum.

An emphasis is placed on storytelling, a traditional and modern method for instructing children in life skills. The "trickster" character of coyote is being used in original stories as a metaphor for the social and environmental influences that students encounter. Grandparents are invited into classroom to share oral histories and to tell about use of traditional foods which are naturally low in fat and high in fiber.

The experimental design includes a comparison of the effectiveness of the curriculum as taught 1) in both fifth and seventh grades and 2) supplemented by a health worker who is working with families to improve diet and avoid tobacco. Outcomes measures include changes in knowledge, attitudes and changes in health behaviors--dietary habits and tobacco use. The researchers are also collecting demographic, normative and anthropometric data.

**Table 9.2 Study Components of Primary Prevention from Cancer in Native American Populations Projects in Oregon, California, New Mexico, and New York.**

Study Components	Oregon	California	New Mexico	New York
Target Population	39 Tribes in OR, ID and WA	American Indian Adults	5th and 7th grade American Indian students	American Indian adolescents
Subjects	Random assignment of tribes to early or late intervention	Random assignment of 14 rural and 4 urban Indian Clinics	Random assignment of classrooms to 1 of 3 interventions	Random assignment of after-school programs to 1 of 3 interventions
Sample Size	39 Tribes	1400 clinic users	500 Native children	Approximately 250 Native American Adolescents
Sites	Tribes located in Idaho, Oregon, and Washington State	Indian Clinics located in Northern California	Alamo, Santa Fe, Crownpoint, San Juan Laguna-Acoma, Thoreau, Borrego Pass, Espanola, Smith Lake (NM); Aneth, UT, Hopi and Keams Canyon (AZ)	Native programs located in Maine, New York, Connecticut, New Jersey, and Rhode Island

## 2. The Medical Research Institute's Project

The Medical Research Institute's, "American Indian Cancer Control Project" targets 14 rural and 4 urban Indian clinics in Northern California. The purpose of this project is to increase long-term smoking cessation among American Indians in the northern portion of the state through the application of a provider-based intervention that can be reproduced throughout the nation.

Smoking cessation has been identified as the most needed area of cancer control intervention by the staff of the 17 American Indian clinics in the Northern California target area, all of whom will participate in the proposed project. In the three-phased study design, a survey of 1400 clinic users will establish the prevalence of smoking and use of smokeless tobacco and identify correlates of tobacco use behavior. The physician-initiated "Quit for Life" smoking cessation intervention model will be modified for use among American Indians in their own clinics. A unique feature of the intervention will be follow-up home visits from Indian



Community Health Representatives, already integral clinic team members. The second phase is a randomized clinical trial in which clinics will be randomly assigned to intervention or control groups. After training of physicians, dentists and clinic staff in the intervention clinics, 1400 patients will be consecutively recruited to participate in the trial, stratified by intervention status and urban/rural setting. Measurement of critical knowledge, attitudes and behaviors will be assessed at baseline, six months and 18 months. In the third phase, analyses will compare biochemically confirmed quit rates as well as motivation and attempts to quit, between intervention and control clinic participants. Quit rates among family members will also be evaluated as a measure of the diffusion of the intervention into the community. This project will thus produce reliable estimates of the prevalence of tobacco use in this population, a culturally appropriate, evaluated adaptation of an effective smoking cessation intervention, culturally specific health educational materials, and will provide the opportunity for American Indian investigators and health workers to develop experience and expertise in cancer control within their own communities.

### **3. The Oregon Research Institute's Project**

The Oregon Research Institute's, "Tobacco Policy Interventions in Northwest Indian Tribes" is targeted to 39 recognized Tribes in the Northwest Portland Area. This study is developing and evaluating a consultative process and materials that will assist tribal councils in creating and implementing more explicit, comprehensive and stringent tobacco use policies. The 39 Tribes have been randomly assigned to early or delayed interventions and changes in tribal policies will be evaluated using tribes as the unit of analysis.

The primary outcome measures will be the extent and comprehensiveness of (a) tribal tobacco use policies and (b) the implementation process including amount of tribal publicity and activity regarding smoking related issues (e.g., cessation resources, articles in tribal newsletters). The impact of the policy intervention on smoking knowledge, norms, attitudes, and to a limited extent, smoking behavior, also will be assessed.

The policy consultation intervention--which includes cessation materials and resources--will be delivered by the Northwest Portland Area Indian Health Board (NPAIHB) which already provides health education and consultation services to the 39 federally recognized tribes in the northwest. The 39 tribes will be matched on relevant variables (e.g., population, existence of current policy) and randomized to either immediate or delayed (20 months later) intervention; all tribes will eventually receive services. Using tribes as the unit of analysis, stringency of policy (coded from archival materials), the implementation process (assessed via observational, archival, and questionnaire data), and the impact of policy on tobacco related attitudes, norms, and intentions as well as smoking cessation maintenance/relapse (assessed primarily by questionnaire data from tribal influential) will be evaluated. The design permits both between condition (immediate vs. delayed) and within-group longitudinal analyses. Based on the project experience and results, a manual and set of guidelines for tobacco policy development and implementation by Indian organizations will be developed for dissemination.

### **4. The Columbia University Project**

"Reducing Cancer Risks Among Native American Youth in the Northeast," project is implementing interventions to prevent cancer among younger Native American populations in the Northeast. The long term objective of the research is to promote effective decision making

among Native American youth in addressing their current dietary habits and prevent habitual tobacco use. Particular emphasis in addressing social learning and skills interventions to help Native American adolescents to develop competence in problem solving, coping, communication and self-esteem are being incorporated into curriculum with input from the Native American collaborators. This study is investigating the use of culturally sensitive approaches for delivering interventions to promote healthy diet and nutrition, and to prevent tobacco use among Native youth. By encouraging and teaching healthy behaviors, the intent of the project is to prevent certain cancers among participating youth.

Over five years, first, the study will construct a 17-week out-of-school based written curriculum to develop skills interventions for reducing cancer risks associated with tobacco use and dietary habits among Native American adolescents. Second, the study will measure the separate and combined effects of interventions for preventive education related to tobacco use and dietary modification among Native American youth. The curriculum will be delivered through an after school program co-sponsored by tribal health programs and urban Indian center programs including, American Indians for Development of Connecticut; Central Maine Indian Association of Maine; Native American Education Program of New York City; North American Indian Center of Boston; Onondaga Nation of New York; Powhatan-Renape Nation of New Jersey; Rhode Island Indian Council; and the Saint Regis Mohawk Nation of New York.

Pre and post-test questionnaires are being utilized to measure knowledge, attitudes, and behavior changes. Eating habits questionnaires and food frequency questions are being monitored throughout the diet and nutrition interventions. Cotinine tests are administered in the tobacco interventions. Evaluation of these curricula is on-going during the interventions as group leaders from the sites are responsible for evaluation each session during the intervention, noting what aspects of the curriculum were effective or not based on the students' participation and involvement.

### **COLLABORATIVE EFFORTS AMONG COOPERATIVE AGREEMENTS**

Collaboration exists in multiple tasks among the grantees. The Avoidable Mortality research teams collaborate on tasks to increase the type of data collected on selected knowledge, attitudes and behavior cervical cancer survey items, whereas the Primary Prevention grantees adopting the survey instrument of developed for use from one project and implemented it in each research site. In addition, the Avoidable Mortality and Primary Prevention grantees have collaborated on joint tasks such as participating on a survey of principal investigators to document the process and procedures utilized to effectively work with Native communities.

The Cooperative Agreement grantees are collaborating on joint publications. For example, the following chart summarizes collaborative publications which are currently in progress.

**Table 9.3 Collaborative Publications - in Progress**

Avoidable Mortality	Primary Prevention	Both Avoidable Mortality and Primary Prevention
Avoidable Mortality Common Paper #1 -- Development of Culturally Appropriate Survey Items for Assessment of KAB of Native American Women about Prevention of Breast and Cervical Cancer	Primary Prevention Common Paper #1 - Tobacco Use Policies & Practices in Diverse Indian Settings	Cooperative Agreement Common Paper #1 - Working with Tribes <u>05/26/93-Paper on Hold</u>
Avoidable Mortality Common Paper #2 -- Results from Common Data Items of Native American Research Projects	Primary Prevention Common Paper #2 - Tobacco and Diet Common Survey items (NM and NY)	Cooperative Agreement Common Paper #2 - Preliminary results from each 8 project
Avoidable Mortality Common Paper #3 -- Cultural Issues in the Development of Cancer Control Programs for Native American Populations.	Primary Prevention Common Paper #3 - Tobacco Common Survey items (OR and CA)	Cooperative Agreement Common Paper #3 -- Collaboration between Native Peoples and Researchers (new paper proposed 05/26/93)

**Collaborative Activities Among Primary Prevention Research Projects**

Collaborative activities refer to those activities that focus on cooperative efforts to develop and implement common protocols across two or more projects in the Program. Program-wide activities and/or commonalities among these projects have occurred in the following: (1) Tribal Tobacco Policy Observational Checklist; (2) Survey of Tribal Leaders about Tobacco Policy; (3) Common Tobacco and Food/Dietary Survey Items for Youth KAB Instrument; (4) Common Tobacco Items for Adult KAB Survey Instrument; and, (5) Research with Tribes Survey. Progress in each of these areas is described below.

*(1) Tribal Observational Checklist*

The purpose of this instrument is to standardize and objectively record observations made by different members of project staff from each of the four Primary Prevention Projects. The observation checklist identifies indications of tobacco awareness, tobacco policy, and tobacco use within specific settings. The form is self explanatory and easy to complete. The observer is asked to note his/her observations for specified areas. The observer/recorder identifies the area where the inventory was implemented, e.g., parking lot, or tribal office reception area and indicates the presence of items such as "no smoking" signs, ashtrays, tobacco awareness posters, and so on.

*(2) Survey of Tribal Leaders about Tobacco Policy*

Research staff from each of the Primary Prevention Research projects volunteered to participate in the implementation of a Tobacco Policy interview. The Tobacco policy data collection instruments and protocol were developed by the Oregon Research team and were reviewed and revised by the Primary Prevention Steering Committee. Each project was responsible for conducting the interview during a tribal site visit. Two key informants from each research site were interviewed independently and their responses compared. The primary informants were the top manager at the site (e.g., tribal chairman, clinical director or school principal), and the secondary informant was from another office. The informants differed among the research projects but attempts were made to interview informants of the same role within each project (e.g., the New Mexico project interviewed the principal and custodian at each of seventeen sites). Informants were asked about the presence and nature of tobacco use policies in various tribal settings e.g., Council meetings, work areas, schools and offices. If written tobacco policies existed, copies were requested and forwarded to the Oregon Research team.

*(3) Common Tobacco and Food/Dietary Survey Items for the Youth KAB Instrument*

Two of the Primary Prevention Projects are focused on youth: New Mexico and New York. Both projects are using changes in knowledge, attitudes and behavior (KAB) of the target population as an outcome measure. Although each project has its own KAB instrument, they have collaborated with one another to include a set of common tobacco and food related items. The common items on the youth questionnaire were developed during a series of telephone conference calls, on site visits by the New York research team to New Mexico, as well as during semi-annual cooperative agreement meetings. The youth questionnaire is being used with fifth and seventh grade children in nine schools for the New Mexico project and with adolescents who are participating in out-of-school activities in eight sites for the New York project. Approximately 25 tobacco and 25 food related items are used in common.

*(4) Common Tobacco Items for the Adult KAB Survey Instrument*

Two of the Primary Prevention Projects are focused on adults: California and Oregon. Each project developed tobacco survey instruments specifically for their own tribal populations, but have collaborated to include some items which are common to both projects. The California project is administering a tobacco survey to 18 rural and urban American Indian clinics in Northern California. The Oregon project is administering the tobacco survey to the members of 39 Tribal councils in the Northwest Portland Area.

*(5) Primary Prevention Collaborative Paper Number 1: Tobacco Policy and Observation Paper*

The Oregon research team drafted the initial paper which summarizes findings from all four research projects. The paper is being critiqued and revised by the Primary Prevention Steering Committee and is scheduled to be submitted for publication during summer 1993.

*(6) Primary Prevention Collaborative Paper Numbers 2 and 3: Tobacco and/or Diet Common Survey Items*

The New York and New Mexico sites are collaborating on a paper which summarizes the results of common survey items. Likewise, the California and Oregon sites are collaborating on a paper which summarizes the results of common tobacco survey items.

### **Collaborative Activities Among Avoidable Mortality Research Projects**

Collaborative activities refer to those activities that focus on cooperative efforts to develop and implement common protocols across all four projects in the Program. Program-wide activities and commonalities among these projects have occurred in the development, revision, and assessment of common items for the knowledge, attitude and behavior survey.

#### ***(1) Common items for the Knowledge, Attitude and Behavior Survey***

Each of the four Avoidable Mortality Research Projects focuses on cervical cancer. In addition, two of the four include breast cancer. One of the outcome measures for these projects is a change in the knowledge, attitudes and behavior (KAB) of the target population as a result of participation in or exposure to the intervention. During one of the initial monthly conference calls, the Avoidable Mortality Steering Committee identified topics areas for common questions on the KAB Baseline Survey. A list of specific questions for each topic area was compiled by extracting selected items from nine existing KAB cervical and/or breast cancer instruments. Between the monthly conference calls, each site met with local community groups to discuss and obtain suggestions regarding specific survey items. Revisions to the potential common items were made via monthly conference calls as well as fax and mail communication. Feedback was also requested from NCI staff regarding the proposed common questions; as well as issues of validity, sequencing of questions and the effect of sequence changes upon validity and reliability; and, survey implementation procedures. The thirteenth draft of the common KAB items were finalized for pilot testing during the summer of 1991. Minor revisions were made in response to issues discovered during pilot testing.

#### ***(2) Avoidable Mortality Collaborative Paper Number 1: Culturally Acceptable Cervical Cancer Survey***

While in the process of developing KAB survey items which were acceptable to each Native American population, the dearth of publications in this area became obvious. Although numerous agencies and organizations cite the need for cultural acceptability of surveys, little is documented regarding the recommended process and/or protocol to determine cultural appropriateness. The Avoidable Mortality grantees have drafted a paper which documents their individual and joint efforts to determine "acceptability" within their respective sites. This draft article is scheduled to be submitted for publication during the summer of 1993.

#### ***(3) Avoidable Mortality Collaborative Paper Number 2: Results from Common Data items of Native American Cancer Research Projects***

Approximately thirty KAB items are common among the research projects. These items have been included in each project's pre and/or post-test survey instrument. Each project has shared the preliminary findings of these thirty items and a paper is being written which highlights the similarities and diversity of responses among the Native American projects.

*(4) Avoidable Mortality Collaborative Paper Number 3: Cultural Issues in the Development of Cancer Control Programs for Native American Populations*

This paper attempts to clarify "cultural sensitivity" and determine what makes one survey instrument or item "sensitive" and another not.

**Collaborative Activities Among All Eight Cooperative Agreement Research Projects**

*(1) Research with Native Communities Survey*

The New Mexico project coordinated and implemented the administration and analysis of questionnaires to all eight principal investigators of cooperative agreements for cancer intervention research in Native American Populations. This survey included open-ended questions requesting that the investigator describe approaches they used in setting up the research project with the Native community, how problems and barriers were overcome, how the on-going relationship with the Native community is being maintained or enhanced and so on. The first two phases of the survey were completed by December 1991. A working draft was compiled by the New Mexico research team May 1993.

*(2) Cooperative Agreement Collaborative Publication Number 1: Working with Native Communities*

The New Mexico project drafted a report for discussion as a potential common publication by the Cooperative Agreement Steering Committee. The Steering Committee voted to implement major revisions in this task in May 1993.

*(3) Cooperative Agreement Collaborative Publication Number 2: Preliminary Results from each project*

The Journal of *Preventive Medicine* is having a special issue which will highlight the preliminary results from each of the cooperative agreement projects. The grantees are assisting one another in the critique of draft articles. The issue will be released early 1994.

**INTERVENTION PRODUCTS**

Each of the eight Native American cooperative agreements have developed products, most of which are currently being assessed as intervention materials. Following implementation of the interventions, the intervention products will be revised and will be available for dissemination Spring 1994.

**Bowman Gray School of Medicine, North Carolina, "Native American Cervical Cancer Prevention Project"**

1. The "Robeson County Tribal Roll Sampling and Interviewing Procedure/Training Manual" (43 pages) provides a detailed description of the tribal roll sampling procedure that was used in Robeson County and a description of the listing and interviewing procedures. Interviewer procedures are specified within the document and utilized as a resource during the interviewer training which included all Bowman-Gray based personnel and interviewers for Robeson County Lumbee Indians. Quality control procedures used at the field site and at Bowman-Gray are also described.

2. The "Eastern Band Cherokee Reservation Sampling and Interviewing Procedure/Training Manual" (50 pages) provides a detailed description of the sampling procedure that was used in Cherokee and a description of the listing and interviewing procedures. Quality control procedures used at the field site and at Bowman-Gray are also described. The participants of the training included all Bowman-Gray based personnel and interviewers on the Cherokee Reservation. NOTE: due to the cultural and geographic diversity of the Lumbee and Eastern Band Cherokee Tribes, separate training manual were necessary.

3. The "Cervical Cancer Prevention Project Intervention Protocol and Plan" (18 pages) specifies the Intervention Protocol. The target group for this document was the NCI Native American Program Director and all Bowman-Gray project personnel. This product was produced at the request of NCI to provide a detailed description of the intervention protocols and plans, specifically Bowman Gray's plans for implementation of intervention.

4. The "Cervical Cancer Prevention Project: A Manual for Project Guides" (51 pages) is the Bowman Gray Intervention Training Manual. This product provides a detailed description of the educational sessions that the project guides conduct with women who have been assigned to the intervention. Also included are supervision and documentation requirements. The target population for this product included all Bowman-Gray based personnel and Project Guides at each field site.

5. The "Native American Cervical Cancer Prevention Project BGSM - Based Follow-Up Policy/Procedure Manual" (13 pages) targets all Bowman-Gray based personnel. This product provides a detailed description for the follow-up of intervention participants after they have completed both educational visits with the project guide. This follow-up is through the mail with the project guide. This follow-up is through the mail and will continue until the end of the project. Also included are copies of follow-up materials.

6. The "Native American Cervical Cancer Prevention Project Policy/Procedures for Pap Data Collection: Cherokee" (4 pages) provides purpose, policies, and procedures for medical chart review at IHS, Cherokee. Personnel policies for medical chart reviewer also included. The target population for the Manual includes all Bowman-Gray personnel and the medical chart reviewer at Cherokee site.

7. The "Native American Cervical Cancer Prevention Project Process Evaluation Policy" (8 pages) is designed for all Native American Cervical Cancer Prevention Project personnel. This product provides a description of purpose, policy, and procedure for evaluation of programs, materials, interviewers, and project guides.

8. "Important Information for Indian Women about the Pap Smear and Cervical Cancer" is an education pamphlet (6 pages) which is disseminated to intervention participants during the research period and to control group participants at the end of the project. The pamphlet was pretested with clinic population and was comprehension tested during the follow up interview. This product provides project participants with the following information: what cervical cancer is, what a Pap Smear is and how it's done, the importance of Pap Smear to early detection of Cervical cancer. Also included are descriptions of Pap Smear results and descriptions of possible treatments after an abnormal Pap Smear.

9. The "Women's Cancer and Eating Smart Quiz" (4 pages; quiz 2, results 2) is designed for intervention participants as an ice breaker as the project guide begins the educational



session. The quiz is administered by the interviewer and addresses a woman's risk for breast, uterine, or cervical cancer by looking at her personal history, habits, and diet. The quiz is completed on the first educational visit and the results returned on the second visit.

10. "Important Information on Cervical Cancer for Native American Women" (10 minutes) is an educational video which describes cervical cancer, the Pap Smear, Pap Smear procedure, and the importance of Pap Smear to early detection of cervical cancer. Also included are descriptions of Pap Smear results and descriptions of possible treatments after an abnormal Pap Smear. The video is used during the initial visit by the Project Guides and may be shown during the follow-up visit if the project guide determines that a review of the information is needed. The video was also utilized during the Training for the intervention personnel. Since the intervention is individualized, the video is used to make certain that all participants receive the same information.

### **American Indian Health Care Association's "Native American Women and Wellness" Project**



1. Four color brochures were developed for Native American women patients at urban Indian, tribal, or IHS clinics. The brochures are (1) "Your Pap Test"; (2) "Your Pap Test Results"; (3) "Treatment and Follow-up Care"; and (4) "The special needs of women over forty". Several steps were undertaken to develop each brochure, including, but not limited to the following: (a) Review findings from KAB survey to identify and address knowledge gaps and risk behaviors; (b) Review and comment of existing materials by field staff and providers (e.g., culture appropriateness, subject matter approval, content level, reading level); (c) Text draft sent to site staff for comments; (d) Illustrations included and text revision in draft color

copy which was sent to clinics (intervention) for pre-test with patients through learner verification review of key points (forms submitted); (e) Revisions made to text and illustrations based on patient comments; and, (f) Final approval by program director. All brochures are written for the 6th grade reading level. These brochures are used by the intervention sites to inform all Native American women of the importance of annual Pap screening, the procedures of the Pap and pelvic exams, and risk factors for cervical cancer. Copies will be made available to control sites after Spring 1994.

2. "We are the Circle of Life" colored poster was designed for Native American women patients at urban Indian, tribal, or IHS clinics. Each intervention site received 50 free posters. An undetermined quantity will be distributed to the intervention sites with an equal amount reserved for the comparison sites. Remaining posters will be sold for cost, \$7.00 each. The posters were designed for fifth grade reading level. The wording on the poster was developed by polling women on common/recurrent themes emerging from the illustration. The poster is being used at the four clinic intervention sites. It is displayed in the waiting room, exam rooms, and staff offices. There are already several requests for the poster from IHS and other state and clinic programs. But all of the patient education materials distribution are limited to the intervention sites through June 1994.



3. "The Native American Women and Wellness Pap Tracking System" (NAWW Pap Tracking System) is a computer software patient registry program targeting Native American women and their Pap Smear and colposcopy history. The computer program utilizes a built in recall system for annual exams and abnormal results modelled on the Bethesda Pap result classification system.

This product is aimed at urban Indian health clinics to assist in the collection of accurate patient/women's health information. The NAWW Pap tracking system was pre-test by the seven site coordinators at each of the field site clinics. Revisions were made and the system was pilot tested with each coordinator. Practice Sheets are on file in Minnesota which summarize the interpretation of the patients' Pap or colposcopy test results. Data utilize the Bethesda classification system. During the baseline data collection, a registered nurse interprets Pap result into the Bethesda Classification. These results are entered onto the Pap Tracking System computer registry. Another registered nurse performs quality assessment of the data/results entered on every third entry. Inter-rater reliability on Pap result interpretation is performed with a second Registered nurse on every tenth result. The NAWW Pap Tracking System is available on one 3.5 inch high density disk with a 65 page manual. The software program is a menu driven format aimed at staff with little to no computer use experience. The manual is also aimed at users with little to no familiarity with software manuals. The manual is estimated to be a tenth grade reading level. The NAWW Pap Tracking System is being used at all seven field sites as the standardized method of patient registry, recall, and follow-up. Preliminary results of the baseline entries from the intervention sites suggest that at least 48%-70% of the clinic patients had not had a Pap test within two years across 4 sites. The protocol for baseline entries is also enclosed.

This system will be an on-going data collection system at all seven sites and incorporates case management functions at intervention sites. The three control sites have an edited NAWW Pap Tracking System. The control sites will receive the comprehensive NAWW Pap Tracking System computer program after June 1994.

4. An untitled 15-17 minute "trigger" video was developed for Native and non-Indian providers (e.g., M.D.s, N.P.s, P.A.s and R.N.s) with little previous experience working with minority/Native American patients. The video is designed to assist the health professional who is providing medical services in urban, tribal, or IHS facilities. This video will be used to train providers about the cultural differences and needs of Native women with regard to cancer screening and women's health care. This video provides the viewer with examples of Native American women perceptions about the delivery of women's health care and cancer treatment. Positive and negative aspects of care are discussed within a cultural context.

#### **The Wai'anae Cancer Research Project**

1. The "Protocols and Procedures Manual of the Wai'anae Cancer Research Project" includes procedures for intervention and evaluation methodology. It is designed to serve as a "blue print" for implementation by other investigators and Native American communities. Anticipated completion date is July 1995. The literacy level will be for Investigators.

2. The "Kokua Group Curriculum of the Wai'anae Cancer Research Project" is targeted to health professionals and para-professionals. Literacy level will be appropriate tenth grade level for para-professionals trained in cancer control and group facilitation. It is currently in draft form and the final length will be approximately 10 pages, plus attachments. This is currently being used to train and provide direction to para-professional outreach workers ("Navigators").

3. A report, "Summary Description of Kokua Groups: Including group characteristics, dynamics and content analysis" will be completed in 1995. The target population is other investigators, health professionals, and Native American communities.

4. "Malama Kekahi I Kekahi" (Taking Care of Ourselves and Each Other) is a project brochure designed for Native Hawaiian women residing on the Wai'anae Coast. Brochure drafts were pre-tested by project staff, and community advisors, and 2 focus groups of women unfamiliar with the project. The brochure is 3 pages in booklet form with a ninth grade reading level. The brochure is used to recruit peer group leaders to hold Kokua Groups, and to promote community acceptance of the project. A second shorter version with a sixth grade reading level will also be produced.

5. "Malama Kekahi I Kekahi: A gift for the Women of Wai'anae" is the Kokua Group Journal and is targeted to Native Hawaiian women participants of the Kokua Groups. The journal has been evaluated by project staff and participants in the pilot Kokua Groups. Because the journal includes reprints and brochures from various sources as well as original material, the literacy level varies, but primarily is between 6th and 9th grade level. The journal will be approximately 50 pages in its final form. The journal contains, in written form, excerpts of information presented orally in the Kokua Groups. It also contains supplementary information and resources. A copy is given to each Kokua Group participant.

#### **Columbia University, New York Project, "Reducing Cancer Risks Among Native American Youth in the Northeast"**

1. Three cancer prevention curricula will be available after June 1994: one on diet and cancer prevention, one for tobacco education and prevention, and a combined diet and tobacco curriculum. The target population for these curricula are Native American youth between the ages of 9 and 11 years. Each of the three curricula are for after school programs and have 17 lessons. Each is approximately 70 pages long. The literacy level of the curricula are targeted for paraprofessional readers, however, a person with some college would find the reading relatively easy.

2. The "Anthology of Traditional Tobacco Stories" is a collection of Native American Tobacco Stories specific to the Northeast region of the U.S. The purpose of this anthology is to emphasize the significance of ceremonial uses of tobacco among Native peoples and to encourage respect for these traditions that do not promote habitual use of commercial tobacco. The Anthology is used during the tobacco prevention interventions by sharing the history of tobacco in the sessions with the youth participants.

#### **The Medical Research Institute's, "American Indian Cancer Control Project"**



1. "It's Your Life" is a smoking cessation motivational video targeting Northern California Indians. The target population for this video is adult American Indian smokers over the age of 18 years. The video was tested via focus groups of community members and input from the Project's American Indian Advisory Board. The video is 16 minutes long. The literacy level of the video is estimated to be 9th grade. The video was used as a motivational tool in the smoking clinic to set a quit date, to quit and remain a quitter. The video was also used as an introductory tool for the clinics and tribal Community Health Representatives to introduce the project to the client.

2. "Its Your Life - Its Our Future, Stop Smoking Guide" (28 pages) is a smoking cessation self-help guide targeting Northern California Indians. The target population for the guide is adult American Indian smokers over the age of 18 years. The self-help guide was tested via focus groups, the Project's American Indian Advisory Board, and the SMOG readability test. The literacy level of the self-help guide is between 5 and 7. This product was distributed to smoking clients to assist them and to provide tips on how to quit smoking and maintenance.

3. The "Community Health Representative/Outreach Worker Training Guide" (15 pages) was designed as a resource for the Community Health Representative (CHR) and Outreach Worker Training sessions. The CHR training manual was tested via pilot tests and one-to-one feedback from CHRs. The training follows the guide and each CHR is given a copy of the manual to assist them as the make home visits.

### **The University of New Mexico's "Southwestern Cancer Prevention Project for American Indians"**



1. "Pathways to Health" is a cancer prevention/health promotion classroom curriculum for fifth and seventh grade American Indian students. The curriculum includes (a) a teacher guide (150 pages); (b) student workbooks (60 pages); (c) curriculum evaluation instruments (pre- and post-test measures - 150 items and a series of student questionnaires); and, (d) an evaluation manual (80 pages). Project evaluation materials include teacher evaluation, student feedback, results of pre- and post-test measures, and evaluation staffs' observation.

Each curricula literacy level is appropriate for the intended audience (e.g. the literacy level for the fifth grade student workbook is at or below the fifth grade level). The Teacher's Guide provides suggestions for implementing the curricula. The Student Workbooks include worksheets and other types of ancillary learning tools. The Evaluation Instruments are completed both before and after the curriculum is taught. The Evaluation Procedures manual serves as a guide for project staff to ensure that all phases of the project are conducted according to standardized protocol.

2. "Teaching the Pathways to Health Curriculum in the Elementary and Middle School Environment" (150 page teacher guide) is the Cancer Prevention/Health Promotion Curriculum Course which was used to train educators to teach the "Pathways to Health" classroom curriculum. It was targeted to elementary and middle school teachers. This document was the primary resource during the two-day training session and was evaluated through participants' evaluations. The literacy level is college.

3. "Pathways to Health Family/Community Curriculum" is designed to compliment the companion classroom and food service curricula, but can also be presented on its own. The target population is American Indian families and the literacy level is at or below the sixth grade level. The product was evaluated with focus groups, audience feedback, and participant observations. It is comprised of a series of workshops, presentations, demonstrations, videos, and brochures focusing on cancer prevention and health promotion lifestyle strategies.

4. "Pathways to Health School Food Service Curriculum" is targeted to school food service personnel providing meals to American Indian students. It is designed to compliment

the companion classroom and family/community curricula, but can also be presented on its own. It is comprised of a series of presentation and demonstrations, videos, and brochures focusing on modifying school meals to meet national guidelines for dietary fat and fiber content. The literacy level is at or below the fifth grade level. The product was evaluated with focus groups, participants feedback, and presenters' observations.

5. "Life in Balance" is a 20 minute video which is designed to motivate and support Native Americans who are in the process of implementing cancer prevention lifestyle changes. It is a documentary of six Native people, age range from 30 to 92, who discuss why they were motivated to make the lifestyle changes, barriers to changes, suggestions for utilization of support systems, as well as how to integrate traditional Native values as an essential component in making choices with positive outcomes. The target population is American Indian adults. The product was evaluated with focus groups, audience feedback, and presenters' observations. The video may be used within the "Pathways to Health Family/Community curriculum", but can also be presented on its own.

6. Cancer Prevention/Health Promotion Food and Tobacco Pamphlets will be developed on various topics such as healthful traditional American Indian foods (i.e., corn, beans, and squash) and the ceremonial use of tobacco. The target population is American Indian students and adults. These pamphlets have a literacy level of third grade and were evaluated with focus groups. These pamphlets are distributed as part of the "Pathways to Health" classroom and family/community curricula, but they can also be used on their own.

7. "Pathways to Health Tobacco Look - Alike Posters" are designed for upper elementary and middle school students. The posters include two pages of instructions and the final product will include two large poster boards and 10 tobacco and look - alike (gum, candy, jerky) items. The literacy level is 1st grade level. The posters are used as a resource for an activity in the "Pathways to Health" classroom curriculum, but can also be used on their own to demonstrate similarities among tobacco and look - alike products. The product was evaluated with teacher and student feed-back, and evaluation staffs' observations.

8. "The Gift of Food - Native American Contributions to the World's Food" (15 pages -- including Teachers' Guide, Student Handouts, maps and pictures) serves as a lesson within the "Pathways to Health" classroom curriculum, but is designed as a free - standing unit. The target population is upper elementary and middle school students. The literacy level is 3rd grade and the product was evaluated with teacher and student feedback, evaluation staff's observations.

#### **Oregon Research Institute's "Tobacco Policy Interventions in Northwest Indian Tribes" Project**

1. "Tribal Tobacco Policy Workbook" (36 pages) provides background information on tobacco health risks and steps to developing a tribal tobacco policy. The target population is tribal council members, tribal health committees and tribal leaders. The first edition was reviewed by researchers at Oregon Research Institute, Oregon State University and Indian health educators at Northwest Portland Indian Health Board. The Workbook was piloted with early intervention tribes, and recommendations for modification for implementation with the late intervention tribes were discussed during July 1992. The literacy level is high school.

The workbook was initially designed to be the core of the intervention. It was (a) distributed to tribal representatives at regional meetings introducing the project; (b) the focus

of local meeting's discussion and problem solving; (c) a referral during telephone consultations; and, (d) a source of sample policy, additional resources, and health facts.

## **SUMMARY**

This Chapter provided a description of the depth and breadth of on-going research activities of the Native American cooperative agreements. These cooperative agreements require sound research design for their individual projects, collaboration with other grantees, development of innovative cancer information or support materials to be utilized during the research interventions. All projects are participating in the preparation of scientific papers to be submitted to juried publications.



# SECTION I

## OVERVIEW OF CANCER AMONG INDIGENOUS PEOPLES

The first section of this publication provides an overview of American Indian and Alaska Native populations, a description of cancer databases and their limitations, an explanation of cancer incidence, mortality and survival data for American Indians and Alaska Natives, clarification regarding the regional variation of cancer among Indigenous Peoples from different geographic regions and tribal affiliations. The last chapter of this section provides a summary chart of risk factors for the eight cancer sites which are common among Native Americans and a brief discussion of tobacco use among Native Americans.







## CHAPTER 10: SPECIAL POPULATIONS STUDIES BRANCH NATIVE AMERICAN CANCER PREVENTION AND CONTROL PROJECTS

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### CHAPTER OBJECTIVES:

- BRIEFLY DESCRIBE THE FOLLOWING SPECIAL POPULATION STUDIES BRANCH NATIVE AMERICAN CANCER INITIATIVES:
    - ◆ R01 INVESTIGATOR-INITIATED NATIVE AMERICAN RESEARCH PROJECTS
    - ◆ NATIVE AMERICAN WOMEN'S CANCER INITIATIVE; REQUEST FOR APPLICATIONS
    - ◆ NETWORK FOR CANCER CONTROL RESEARCH AMONG AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS
    - ◆ TRADITIONAL FOODS CAN BE HEALTHY PAMPHLET
    - ◆ THE GREAT ALASKA SPIT-OUT
    - ◆ DOCUMENTATION OF THE CANCER RESEARCH NEEDS AMONG AMERICAN INDIANS AND ALASKA NATIVES
    - ◆ THE SCIENCE ENRICHMENT PROGRAM
    - ◆ EXHIBIT ON CANCER IN AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS
    - ◆ CANCER PREVENTION AND CONTROL WORKSHOP FOR AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS
    - ◆ AMERICAN INDIANS AND ALASKA NATIVES CANCER PROGRAM/RESEARCH RESOURCE DIRECTORY
    - ◆ INTRA-AGENCY AGREEMENTS WITH INDIAN HEALTH SERVICE ALASKA NATIVE TUMOR REGISTRY
    - ◆ INTRA-AGENCY AGREEMENTS WITH INDIAN HEALTH SERVICE RESEARCH PROGRAM, TUCSON, ARIZONA
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### INTRODUCTION

The Special Populations Studies Branch, Cancer Control Science Program, Division of Cancer Prevention and Control, National Cancer Institute (NCI) has implemented a variety of culturally appropriate and competent cancer prevention and control initiatives since 1988 which focus on American Indians and Alaska Natives. In addition to the cooperative agreements which were described in the previous chapter, this chapter provides a brief description of each of those Native American initiatives.

**R01 INVESTIGATOR-INITIATED NATIVE AMERICAN RESEARCH PROJECTS 1989-1992**

The NCI has a multitude of mechanisms which are used to fund research. The "R01 Research Project Grant" is the mechanism that is generally referred to as a traditional research project. It differs from cooperative agreements in a variety of ways (see chart this page). The R01 is a grant idea which is initiated by the investigator. A R01 may be "solicited" by the government through a request for applications (RFA) or a program announcement (PA), or it may be "unsolicited" and developed independently by the investigator. R01s are awarded to support a discrete, specified research project to be performed by the named investigator in an area representing his or her specific interest and competencies. In a "traditional" grant, the investigator has autonomy; government cannot be directive of investigators. Government staff can provide general technical assistance; staff can make suggestions but cannot assist in writing any portion of the application; and staff cannot select the research design, and so on.

The Special Populations Studies Branch released a request for applications (RFA) in 1988 for Native American developmental research. In response to that RFA, two applications were funded.

**Cervical Cancer Among American Indian Women**

1. Grant Identification Number: R01-CA49553
2. Title of Research Project: Cervical Cancer among American Indian Women
3. Principal Investigator: Gail Farmer, Dr.P.H., California State University, Long Beach

4. Abstract:

Farmer's, "Cervical Cancer Among American Indian Women" was a three year project implemented in Southern California. The California State University Long Beach and the American Indian Free Clinic, located in Los Angeles County, collaborated to develop and administer a culturally sensitive cervical cancer knowledge, attitudes, and behavior instrument to Indian women residing in the greater Los Angeles-Orange County area. The project aims were to (1) assess the need for cervical cancer control interventions; (2) determine the barriers to cancer control programs; and, (3) develop a culturally sensitive instrument for data collection. This instrument was used to determine the prevalence of cervical cancer symptoms; determine the prevalence of risk factors; measure, knowledge, attitudes, practices; and assess accessibility and acceptability of cervical cancer screening and treatment. The total sample size was 1500 American Indian women, 800 American Indian women participated in the pilot test and 700 for the final survey.

5. Sample Size: 800 persons for pilot test, 700 for final survey
6. Demographics of Target Population: Native American females
7. Site/Geographical Region(s): Southern California
8. Budget: \$300,000
9. Year Funded: 1989

10. Duration of Project: 3 years

### **The Sioux Cancer Study**

1. Grant Identification Number: R01-CA49522
2. Title of Research Project: Cancer Control and Cancer Risk Factors Among Sioux Indians
3. Principal Investigator: Thomas Welty, M.D., M.P.H., Aberdeen Area Indian Health Service, Rapid City, SD
4. Abstract:

The purpose of Welty's "Sioux Cancer Study" was to assess cancer mortality and cancer risk factors among 1,521 Sioux Indians aged 45-74 who were members of the Devil's Lake, Cheyenne River, and Oglala Sioux Tribes. The adequacy of screening for cervical, uterine and breast cancer and the acceptability of screening programs in a high risk age group of Sioux women was determined.

During this study, three instruments were designed, pilot tested and utilized. The knowledge, attitudes and beliefs questionnaire for cervical and breast cancer (Mammography Survey I) - This questionnaire was administered to all women who were participants of the Sioux Cancer Study and who came to receive mammography screening as part of this study. Through the grant, screening mammography was provided to 559 women in their target communities. In communities where mammography screening was provided through the mobile unit, the KAB survey was also administered to women who did not come in to receive the mammography screening. The responses in participants and non-participants in the Mobile Screening Program were compared. Patient satisfaction questionnaire (Questionnaire for Mammography Participants) - This questionnaire was administered to all women after they had received mammography screening and was helpful to assess the response of screening from Sioux women. Non-participant questions (Mammography Survey II) - Women who did not return for the screening mammogram were contacted and if they consented, the questionnaire was administered to determine why they did not participate in the screening.

5. Sample Size: 1500 for survey, screening; 1400 men and women for case control study
6. Demographics of Target Population: Sioux Indians (males and females)
7. Site/Geographical Region(s): Community Intervention, Devils Lake, Pine Ridge and Cheyenne River
8. Budget: 400,000 million
9. Year Funded: 1989
10. Duration of Project: 3 years

## **NATIVE AMERICAN WOMEN'S CANCER INITIATIVE (NAWCI) REQUEST FOR APPLICATIONS (RFA)**

The Special Populations Studies Branch (SPSB), Division of Cancer Prevention and Control (DCPC), National Cancer Institute (NCI) released a request for applications (RFA) for the Native American Women's Cancer Initiative (NAWCI) during the summer of 1993. This RFA invites grant applications from organizations to participate in research to develop and determine the effectiveness of cancer control and prevention intervention strategies in Native American women, including American Indian, Alaska Native, Native Hawaiian and/or American Samoan women. The long range goals of this initiative are to improve cancer survival rates and reduce cancer mortality rates among Native American women through cancer prevention and control efforts.

### **Background**

In 1987 the NCI sponsored a working group on cancer among Native Americans. As a result of that meeting, two Requests for Applications were issued in 1989 (one on avoidable mortality from cancer among Native Americans and the other on primary prevention of cancer among Native Americans). Eight awards were made for these RFAs, four for avoidable mortality and four for primary prevention. The target populations for these five year cooperative agreements were reservation and rural American Indians, urban American Indians, Alaska Natives (urban and rural), and Native Hawaiians.

The *Native American Women's Cancer Initiative* (NAWCI) evolved from these five year cooperative agreements. Based upon the preliminary findings, this initiative has been developed to appropriately respond to emerging cancer needs and issues of Native American women. At the turn of the century, cancer was an extremely rare disorder among American Indian people (Hrdlicka, 1904, Jones, 1989, p.45). Although American Indians and Alaska Natives continue to experience low cancer incidence rates in comparison with other racial groups such as whites, blacks, and Asians, within the last few generations, cancer has become the leading cause of death for Alaska Native women, and is the second leading cause of death among both American Indian and Native Hawaiian women. (Department of Health and Human Services, IHS Trends, 1992, p. 34, IHS, Cancer Mortality, 1992).

A report entitled, "*A National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives*" was prepared by the NCI-supported *Network for Cancer Control Research among American Indian and Alaska Native Populations*. The purpose of this plan is to enhance the awareness in federal agencies and in others about the problems of cancer among American Indian and Alaska Native populations. This plan emphasizes the poor cervical and breast cancer survival rates, the lack of access to early detection services, the lack of Indigenous health care providers and researchers, and the cultural barriers which interfere with effective cancer prevention and control programs (Network, 1992, pp. 8-10, 24, 26-28, 30, 32 and 35).

Numerous barriers have been identified which interfere with cancer prevention and control efforts among Indigenous women. These barriers include but are not limited to culturally inappropriate recruitment protocols, lack of culturally appropriate cancer prevention and control materials and programs, inaccessible science and/or research educational and

training opportunities, English as a second language, poverty, transportation, cancer causation beliefs, lack of Native health providers, and unavailability of health facilities. The types and impact of such barriers vary among Native communities in different regions of the country.

Multiple factors may contribute to cancer among Native American women which differ from women of other races, and differ among Indigenous women due to genetic factors, acculturation, and socioeconomic status.

### **Objectives**

The research studies will determine the effectiveness and efficacy of cancer control and prevention intervention strategies which are designed to address one of the following objectives: (1) address the barriers to culturally appropriate quality cancer control services including screening, appropriate follow-up, diagnostic, treatment and rehabilitation programs for cancers which are common and/or disproportionately elevated within Indigenous women; (2) reduce cancer risk behaviors in Native American women (e.g., high dietary fat intake, tobacco use, alcohol consumption); or, (3) assist in providing technical assistance to improve Native American women's research skills and eventually increase the number of Native American women who are in key research positions (e.g., principal investigators).

### **Funding**

Approximately \$1.5 million in total costs per year for four years will be committed to specifically fund applications which are submitted in response to this RFA. It is anticipated that up to five awards will be made, at least one from each option noted below. The total project period of these awards may not exceed four years.

### **Research Options**

The Native American Women's Cancer Initiative will address cancer prevention and control among Native American women through a request for applications (RFA) which has three options: Option A focuses on common/disproportionate cancer rates and barriers to early detection services; Option B emphasizes reduction of risk factors; and, Option C stresses research capacity development among Native American women. It is anticipated that up to five awards will be made, at least one from each option. The total project period of these awards may not exceed four years. The applicant must specify which option is the focus in the application and it is recommended that only one option be the focus of any application.

#### **Option A: Common/Disproportionate Cancer and Barriers**

Cancer Intervention Research in Native American Women grants focus on cancers which are more common among Native American Women and support the development of long-term intervention strategies. These projects will develop, implement and evaluate interventions which are designed to overcome the barriers which Native American women experience to access culturally appropriate quality cancer control services including screening, appropriate follow-up, diagnostic, treatment and rehabilitation programs. The efficacy and effectiveness of these culturally appropriate interventions will be assessed. These projects will focus on cancers which are more common among Native American women from a specified area (e.g.,

breast cancer among Native Hawaiian women, or gallbladder cancer among Southwestern Indian women, or lung cancer among Alaska Native women), or they may address the unusually aggressive forms of cancers in Native American women.

#### **Option B: Risk Factors**

Cancer Risk Factors among Native American Female Populations will develop, implement and assess cancer prevention and control interventions which are designed to reduce risk factors of this population in regions of the country where the cancer control needs of American Indian and Alaska Native women have been increasing and data are sparse (e.g., Northern Plains region, Northwestern U.S., Northeast U.S., Southeast U.S., remote Alaska Native Villages). Unusual behaviors, such as frequent use of smokeless tobacco, or high consumption of smoked, high fat foods; or access to high fat commodity as a sole source of food availability may be emphasized.

#### **Option C: Research Capacity Development**

Research Capacity Development Workshops will be designed to provide technical assistance to increase the research application and scientific skills of Native American women. The aim of these workshops is to increase the number of Native American women who pursue research careers and/or become co-investigators or principal investigators of NCI research projects. These grants would involve developing and implementing workshops in different hard-to-reach Native populations and providing them with technical assistance in the development of research ideas and applications. The effectiveness of these workshops will be evaluated. The Research Capacity Development workshops will be limited to human research and the clinical-behavioral fields only.

The aim of the Native American Women's Cancer Initiative is to support studies in four or five different geographic regions of the United States. Although every attempt will be made to provide regional representation, the possibility exists that applications may not be awarded for all geographic regions and/or Native American populations.

Intervention strategies may differ between Native Americans living in urban areas, those remaining on reservations or villages, and/or those residing on American Samoa or Hawaii. All such groups are eligible for study under this RFA.

The National Cancer Institute considers it essential that multiple and key Native American community organizations and groups be involved in the development and implementation of comprehensive, community-wide programs to prevent and control cancer within communities. The NCI recognizes the heterogeneity of Native American women and their unique status of being from Sovereign Nations.

## NETWORK FOR CANCER CONTROL RESEARCH AMONG AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS

### Background

The Special Populations Studies Branch (SPSB) of the National Cancer Institute (NCI) has supported the development of a *Network for Cancer Control Research among American Indian and Alaska Native Populations* from April 1990 to the present. At the turn of the century, cancer was a rare disorder for the American Indian and Alaska Native. However, over the last two decades, cancer rates for these populations have increased significantly to be the third leading cause of death for all ages, and **the second leading cause of death** for those over age 45. In addition, American Indians and Alaska Natives have the **poorest survival rate** of any *racial* group for all sites of cancer. As a result, both Drs. Sullivan and Mason have emphasized the need to increase and/or improve Public Health Services to minority and low literacy groups. This Network is one of several efforts to accomplish the health objectives in the Department of Health and Human Services Healthy People 2000 Report and the NCI Year 2000 Objectives.

### The Mission Statement

Cancer incidence and mortality among American Indian and Alaska Natives have increased in this century. In an effort to restore this special population to a state of good health, the Network's mission is to improve the health of American Indian and Alaska Native peoples by reducing cancer morbidity and mortality to the lowest possible levels and to improve cancer survival through cancer control research.

### The Network Steering Committee

The Network Steering Committee is comprised of fifteen participants, at least two-thirds of whom are of Native descent. Members are selected to become participants of the Network Steering Committee based upon the following criteria:

1. Professional Background. Individuals possessing two or more of the following:
  - (a) Demonstrated commitment to the provision of culturally appropriate and quality care to Alaska Native and/or American Indian people.
  - (b) Successfully conducted culturally relevant research with American Indian and Alaska Native populations.
  - (c) Possess expertise in the field of oncology.
  - (d) Provide or direct health services/clinics targeting American Indian or Alaska Native populations.
2. Geographic Distribution (Major geographic regions of the "lower 48" and of Alaska are represented)
3. Tribal Representation (members include multiple tribal backgrounds)
4. Gender Representation (approximately equal distribution of both genders)

## 5. Settings/Sites Represented (e.g., urban, 93-638 contracts, reservations)

There are three types of Network memberships. *Official individual memberships* are non-government individuals who have voting privileges. *Official organizational memberships* are individuals who represent a national Native American organization and also have voting privileges. *Ex-officio memberships* are non-voting federal representatives. The ex-officio members include six representatives from the Indian Health Service, two representatives from the National Cancer Institute, and two representatives from other ethnic research networks. The ex-officio representatives are professionals who have demonstrated a commitment to improving the health of Native Peoples and other underserved populations.

The Special Populations Studies Branch (SPSB) of the NCI has provided leadership and technical assistance support during the developmental stages of the research network. SPSB staff are not official members of the Network and do not vote.

### Functioning of the Network

The *Network Steering Committee for Cancer Control Research among American Indian and Alaska Native Populations*, sponsored by the Special Population Studies Branch, NCI, has been designed to develop and promote a cadre of cancer prevention and control scientists to conduct culturally sensitive research among American Indian and Alaska Native populations. The primary objective of this research is to reduce morbidity and mortality from cancer. Toward reaching this objective, the Network may: (1) carry out research; (2) affiliate with other groups to carry out research; and/or, (3) facilitate research by encouraging training of new researchers.

In the future, the Network Steering Committee will continue to develop new goals and objectives and continue to serve as the decision-making body. However, membership for the Network itself will be open to those who are interested in culturally appropriate cancer research among American Indian and Alaska Native people.

### Accomplishments of the Network

Several tasks have been completed as a result of the Network Steering Committee's participation and/or suggestions. Examples of each fiscal years' accomplishments follow (sequenced from most recent fiscal year to past years):

#### Fiscal Year 1992 Accomplishments

Accomplishments during fiscal year 1992 (Year 03 of the Network's existence) include the following:

1. *A National Strategic Plan for Cancer Prevention and Control Research among American Indians and Alaska Natives* was developed throughout FY 1992 and was presented to Department of Health and Human Service administrators and other leaders during the latter part of 1992. The Strategic Plan includes a brief overview of the cancer problem among indigenous people, a summary of major concepts and recommendations for federal agencies. Each concept and recommendation identifies appropriate action



items, rationale for the action item and outcomes. The Network will provide an addendum to the Strategic Plan each fiscal year.

2. A NCI-supported conference application (R13), "Cancer in Indian Country" was submitted and awarded to the Native American Research and Training Center (NARTC) of the University of Arizona. The application was developed at the request of the NCI-sponsored *Network for Cancer Control Research among American Indian and Alaska Native Populations*. This conference was held in September 1992 in Rapid City, South Dakota. It was the Network's intent that this conference be the first of a series of regularly scheduled (annual or bi-annual) national meetings among professional and lay Native peoples, and provided the opportunity for federal agencies to interact and improve their present working relationship with indigenous Peoples. The conference provided national networking opportunities among Natives, tribal leaders and researchers. The majority of Native conferences are held in the Southwest which is beneficial to local Natives, but cancer continues to be less of a problem in the tribes from that area. This conference was held in the Northern Plains areas because this region has the most severe cancer problem among American Indians in the lower 48 States (the cancer problem is even more significant in Alaska, but travel to Alaska would eliminate Native participation). Since the conference objectives included increasing the awareness of cancer as a problem among lay Natives, as well as involving indigenous people in the research process, the location allowed Northern Plains people less expensive access to the meeting.

The goals and objectives of this conference were consistent with the mission of the NCI and complemented a variety of NCI current or planned Native American Projects. In addition, it demonstrated a national networking effort for hard-to-reach and low SES populations. It also provided a real forum for lasting interaction with the NCI and Native Peoples. The conference provided a core for future Native cancer research and training activities.

### **Fiscal Year 1991 Accomplishments**

Accomplishments during fiscal year 1991 (Year 02 of the Network's existence) include the following:

1. A "Cancer Education Program Survey" was developed and distributed to American Indian and Alaska Native urban, Reservation, and IHS and Native-operated health clinics; tribal councils; tribal health planners, Native organizations and associations; as well as Native health care providers and allied health professionals. The purpose of the survey was to identify the types of cancer-related activities in progress among American Indian and Alaska Native peoples.
2. A grant proposal to offer a conference on "Cancer among American Indians and Alaska Natives: Getting Healthy Again" was developed. The proposal was submitted to federal agencies for funding during the fall of 1991. This proposal was developed independent of NCI SPSB support.

3. The initial draft outline of a "National Strategic Plan for Cancer Control among American Indians and Alaska Natives" was completed. This material was scheduled to be revised and finalized during the fall of 1991.

During fiscal year 1990 (year 01 of the Network Steering Committee), the following tasks were completed:

#### **Fiscal Year 1990 Accomplishments**

1. Long range goals, objectives, and tasks were identified.
2. Sub-committees were formed which were comprised of members of the Network Steering Committee: (1) data collection and research; (2) education and training of researchers and providers; and (3) advocacy and funding.

In addition, the Network Steering Committee assisted the *American Indian Alaska Native Caucus* (as recognized by the American Public Health Association), in the development of a Newsletter and compilation of a mailing list. The Newsletter was distributed *by the Caucus* to over 300 professionals who are interested in public health issues and research targeting American Indian and Alaska Native people.

The Network Steering Committee has also provided guidance in the development of a culturally specific exhibit which promoted cancer prevention and control among American Indians and Alaska Natives. The exhibit was designed to be a portable display for conferences and meetings to assist in raising cancer on the health agenda of American Indian and Alaska Native people which was the primary goal of the "Advocacy" Sub-Committee.

The Network Steering Committee has also provided technical assistance to organizations such as the Native American Research and Training Center in Arizona in the development of the first draft of a questionnaire to survey physicians who treat American Indian and Alaska Native cancer patients. The instrument was revised and implemented during 1991.

The Network Steering Committee also provided assistance in the development of culturally specific cancer prevention promotional materials (e.g., bookmarks and tote bags) for distribution to American Indian students and professionals attending specific conferences and meetings.

## Network for Cancer Control Research among American Indian and Alaska Native Populations

### OFFICIAL VOTING MEMBERS

#### CHAIR

James W. Hampton, M.D. *[Choctaw/Chickasaw]*  
Oklahoma City, OK

Thomas Becker, M.D., Ph.D.  
Albuquerque, NM

Julia Davis *[Nez Perce]*  
Lapwai, ID

Mark Dignan, Ph.D.  
Winston-Salem, NC

Cecelia Fire Thunder *[Oglala Sioux]*  
Martin, SD

Gerald Hill, M.D. *[Klamath]*  
Duluth, MN

Jennie R. Joe, Ph.D., M.P.H. *[Navajo]*  
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Judith Kaur, M.D. *[Choctaw/Cherokee]*  
Bismarck, ND

Martin C. Mahoney, Ph.D.  
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Carol Marquez-Baines, M.P.H. *[Luiséno/Paiute]*  
St. Paul, MN

Billy Rogers, M.P.H. *[Kiowa]*  
Norman, OK

Beverly Singer, M.A. *[Santa Clara Pueblo]*  
New York, NY

Anne Walker *[Inuit]*  
Anchorage, AK

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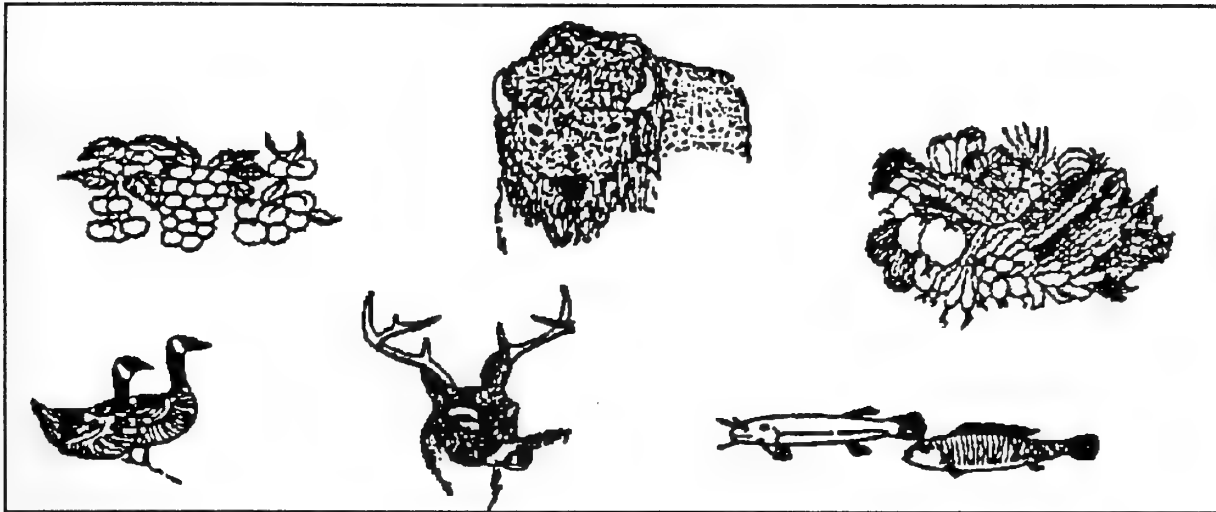
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Linda Burhansstipanov, Dr.P.H. *[Cherokee]*  
Native American Cancer Control, SPSB

## TRADITIONAL FOODS CAN BE HEALTHY



The *Traditional Foods Can Be Healthy* pamphlet was originally developed by the Native American Indian Women's Health Education Resource Center of South Dakota. It was developed for another National Cancer Institute (NCI) project and describes the cancer prevention benefits of consuming traditional American Indian foods. The NCI pretested the pamphlet with American Indian populations living in six geographically diverse settings. Modifications were made based upon the pretesting suggestions.

The Special Populations Studies Branch's duplicated and disseminated a limited number of copies. Feedback from community members included suggestions that the pamphlets be printed on lighter colored paper for ease in reading. This second run of copies was disseminated to Native Americans for their use and suggestions.

The pamphlet received an official publication number during Spring 1993 (NIH Pub. no. 93-3548).

### To Request Copies.

When placing an order, please specify the NIH Publication Number 93-3548, *Traditional Foods Can Be Healthy*. For bulk copies, call 1 (800) 4-CANCER and ask to speak to the Outreach Coordinator. The Outreach Coordinator will take bulk order and process the request. The Outreach Coordinator can also apprise the caller of additional cancer informational materials which are available free of cost.

### Indian Health Service Employees.

For people who work with Indian Health Service, the NCI has provided a camera-ready copy of the pamphlet to the Program Director of the Nutrition and Dietetics Section. The Director has agreed to coordinate efforts for distribution and billing within IHS. For further information, contact Nutrition and Dietetics Section, IHS Headquarters, Rockville, (301) 443-1114.

## **THE GREAT ALASKA SPIT-OUT 1989-1992**

### **Purpose**

The Great Alaska Spit-Out was initiated in 1989 to educate Alaska Native school children and other community members about the health risks associated with smokeless tobacco use.

### **Description of the Contest**

The Great Alaska Spit-out is a contest which is supported by the National Cancer Institute and coordinated and implemented by the Alaska Area Native Health Service, Dental Program.

All school children living in rural Alaska communities are eligible to participate. Alaska Native school children in grades 7 through 12 prepare essays (500 words) or public service announcements (PSA) (½-2 minutes) of smokeless tobacco and cigarette smoking and the harmful effects of their use. Topics may cover the behavioral or physical effects of tobacco use. The poster contest is open to children in kindergarten through sixth grade. The essay and PSA contest is for students in grades seven through twelve. The poster, essay and PSA contest address the issues of smokeless tobacco and cigarette smoking and the harmful effects of their use. Topics cover the behavioral or physical effect of tobacco use.

### **Prizes**

All entrants receive a certificate of recognition for their efforts. The grand prize winner in the Poster Contests receives \$50, the next five winners are awarded \$25 each and the next 45 winners receive \$10 each. The top four essay winners and the PSA winning team (one team of up to three students) receives a free trip to Washington, D.C., to meet with the National Cancer Institute Director, Dr. Samuel Broder, and with Health and Human Service officials.

### **The Great Alaska Spit Out Tobacco Use Survey**

As part of the Great Alaska Spit Out, The Alaska Area Native Health Service has implemented a survey to approximately 1, 570 students.

Alaska Natives have among the highest use of both cigarettes and smokeless tobacco in the nation. Tobacco use in this population begins at an early age.

1990 survey of school children in Alaska

- ◆ Age at which Alaska Native children begin using tobacco: 3 - 17 years
- ◆ 34% used tobacco 5-10 times per day
- ◆ 54% used tobacco 2 to 3 times a day

Survey of 5 villages in Northwest region of Alaska

- ◆ 56% of the adults smoke
- ◆ Of the 216 children in kindergarten through 3rd grade, 8% have tried smoking

- ◆ Of the 161 children in 4th through 6th grades, 10% reported smoking, with girls smoking as much as boys
- ◆ Of the 319 children in 7th through 12th grade, 41% reported smoking, with girls exceeding boys' rates of smoking.

## DOCUMENTATION OF THE CANCER RESEARCH NEEDS OF AMERICAN INDIANS AND ALASKA NATIVES

### Purpose

The Native American Cancer Control Program, SPSB, has suggested that a series of monographs be developed during fiscal years 1993 and 1998 to serve as resources and references to assist in the formulation of culturally competent cancer prevention and control research projects or programs. No single monograph will be designed to be all encompassing nor comprehensive, but rather to complement one another as an integrated and coordinated series of publications.

The information from these publications may be used to assist Native researchers in the development and implementation of cancer intervention programs in urban, rural and/or Reservation settings; in the development of culturally competent Native American survey instruments for the collection of accurate data; and/or in the development of culturally sensitive Native American cancer education materials and programs to be used in innovative research interventions.



### Target Audiences

The monographs will be designed for Native and Non-native cancer researchers, health care providers, tribal health planners, health educators, community health representatives, and other similar professionals working with Native American populations in developing and designing cancer prevention and control research proposals, programs, and/or materials.

### The Native American Populations

When the National Cancer Institute (NCI) specifies, "Native American", the following populations are included: American Indian, Alaska Natives, Native Hawaiian and American Samoan.

### Monograph #1:

Monograph #1, *Documentation of the Cancer Research Needs of American Indians and Alaska Natives* provides an overview of cancer among Indigenous Peoples. The monograph has three sections: the initial section is a brief overview of cancer among Indigenous Peoples; the second section describes the role of nutrition in cancer prevention and control; and, the third section is an overview of NCI-supported Native American projects and activities. It is designed to be used as a resource or reference to assist in the formulation of culturally



competent cancer prevention and control research projects or programs. It is a *brief* overview of the cancer problem among American Indian and Alaska Native People living in urban, rural, Reservation and village sites. It is not designed to be read from cover to cover, but rather that the reader will utilize sections which are appropriate and may assist in the formulation of a cancer prevention and control program for one's local Native community. This publication focuses on American Indians and Alaska Natives only. Subsequent publications will focus on Native Hawaiians and American Samoans as well as American Indians and Alaska Natives.

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SUBSEQUENT SUGGESTED PUBLICATIONS FOLLOW:

- Monograph #2: Documentation of the Cancer Research Needs of Native Hawaiians and American Samoans
- Monograph #3: Cancer Risk Factors among Native Americans
- Monograph #4: Planning Cancer Prevention Research Projects among Native Populations
- Monograph #5: Initiating Local Native Support for Cancer Prevention and Control Programs
- Monograph #6: Participation with and Recruitment of Native Americans in Clinical Trials and other types of Research Projects

## NATIONAL CANCER INSTITUTE'S SCIENCE ENRICHMENT PROGRAM

### Background of Pilot Years 01 and 02)

During the Spring of 1989, Dr. Samuel Broder, Director, National Cancer Institute, met with Dr. Claudia R. Baquet regarding his concerns and ideas about developing an innovative, dynamic training program designed for minority and underserved students. Dr. Baquet was assigned the task of developing such a program. Dr. Broder's idea was formulated and implemented during the summer of 1990 as the **National Cancer Institute's Science Enrichment Program**, a two year pilot project.

An external advisory committee was formed in order to provide advice to NCI. The **Science Enrichment Program Advisory Committee** was comprised of eleven members with special areas of expertise. Subcommittees were established which actually functioned as working groups. They met regularly as either small committees or as a complete committee approximately once a month from September 1989 to May 1990. Several of these meetings extended into the late evening hours and many were on weekends.

#### 1990 Participants

- o 107 students
- o Recruited from approximately 25 States (including Alaska and Hawaii, and the District of Columbia)
- o Incoming tenth grade students
- o Interested in science, mathematics, and/or computer science
- o Selected by a Panel (SEP Advisory Committee)
- o "underrepresented minorities" in the Sciences and "underserved youth"
- o Approximately equal number of males (49) and females (58)

#### 1991 Participants

- o 145 students
- o Recruited from approximately 30 States (including Alaska and Hawaii) and the District of Columbia and American Samoa
- o Incoming tenth grade students
- o Interested in science, mathematics, and/or computer science
- o Selected by a Panel (SEP Student Selection Committee, Advisory Committee)
- o "underrepresented minorities" in the Sciences and "underserved youth"
- o Approximately equal number of males (69) and females (76)

### 1990 Faculty and Support Staff

- o Recruited from approximately 6 States
- o Comprised of Hispanic, Black, American Indian, Asian, and Caucasian ethnic groups
- o Administrative Staff
  - + Director (Project Manager)
  - + Coordinator
  - + 2 Clerical Support
- o Nine teachers
  - + 2 Biology
  - + 2 Mathematics
  - + 2 Computer Science
  - + 1 Chemistry
  - + 1 Physics
  - + 1 Language Arts
- o 2 Recreation Leaders
- o 8 Instructional Aides
- o 5 Female Resident Hall Counselors
- o 5 Male Resident Hall Counselors

### 1991 Faculty and Support Staff

- o Recruited from approximately 8 States
- o Comprised of Hispanic, Black, Asian, and Caucasian ethnic groups
- o Administrative Staff
  - + Asst. Dir. Academic Affairs
  - + Asst. Dir. Logistics
  - + 2 Clerical Support
- o Twelve teachers
  - + 2 Biology
  - + 2 Mathematics
  - + 2 Computer Science
  - + 2 Chemistry
  - + 2 Physics
  - + 2 Language Arts
- o 2 Recreation Leaders
- o 4 Instructional Aides
- o 6 Female Resident Hall Counselors
- o 6 Male Resident Hall Counselors
- o 15 Student Council Members

### NCI SCIENCE ENRICHMENT PROGRAM REQUESTS FOR APPLICATIONS

The first two pilot years of the Science Enrichment Program were overwhelming successes. Based upon its success, in 1991 an RFP was released and among the awardees was the American Indian Science and Engineering Society (AISES), the "National Summer Health Sciences Program".

In May 1992, seven other organizational components of the National Institutes of Health participated with the National Cancer Institute (NCI) in awarding four two-year contracts (with two-year options) for Science Enrichment Programs (SEP) to be conducted at four separate geographical sites within the United States. One such contract was proudly awarded to the **American Indian Science and Engineering Society (AISES) in Boulder, Colorado**. This decentralized approach to SEP builds upon the success of the NCI two-year centralized pilot program (1990 & 91) where over 250 student participants came from as far away as Alaska, Hawaii, and American Samoa.

The Science Enrichment Program is a four to six-week residential science education/training opportunity designed to encourage youth from underrepresented minority and underserved populations (African Americans, Hispanic Americans, Native Americans [*American Indians, Alaska Natives, Native Hawaiians*], and youth from areas where science education opportunities are generally limited or non-existent) to pursue professional careers

in science research fields. SEP addresses the critical need to replenish the Nation's supply of health scientists and health professionals that will be required for the future.

The American Indian Science and Engineering Society is a private, non-profit organization which nurtures building of community by bridging science and technology with traditional native values. Through educational programs, AISES provides opportunities for American Indians and Alaska Natives to pursue studies in science, engineering, business, and other academic areas. The trained professionals then become technologically informed leaders within the Indian community. AISES' ultimate goal is to be a catalyst for the advancement of American Indians as they seek to become self-reliant and self-determined members of society.

Last year, 1992, the AISES program was conducted at the Colorado School of Mines and involved 28 American Indian students (*17 females, 11 males*) from Arizona, Colorado, Montana, New Mexico, North Dakota, Oklahoma, Utah, and Wyoming.

The 1993 program will be conducted at the University of Colorado and is expected to involve 30 incoming tenth-grade American Indian students from the same geographical areas mentioned above.

It is anticipated that other American Indian students will be selected for participation in the other three SEP programs that will be conducted at the following sites:

- University of Kentucky at Lexington
- University of Massachusetts at Amherst
- University of Southern California at Los Angeles

All programs include (1) classroom instruction, (2) hands-on experience with laboratory techniques and computer equipment, (3) special seminars, (4) relevant field trips, and (5) cultural activities.

Post-program evaluations completed by students, staff, and faculty indicate that the SEP experience is very beneficial academically. Separate reports from students and their parents indicate that the students also receive positive influential guidance for personal development during the program.

For further information regarding the AISES "Summer Health Sciences Program" contact: Ms. Cathy Abeita, Director, PreCollege Student Programs, AISES, 1630 30th Street, Boulder, Colorado 80301, (303) 492-8658.

## EXHIBIT ON CANCER IN AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS

Based upon the recommendation from the *Network for Cancer Control Research among American Indian and Alaska Native Populations*, the Special Populations Studies Branch designed and developed an exhibit on Cancer in American Indian and Alaska Native populations. The purpose of the exhibit is to help raise "cancer" on the health agenda of Native lay populations and researchers; apprise Native people of the significant problem of cancer within their tribal communities (eliminate the myth that cancer only occurs in white and Black racial groups); apprise Native people of NCI-sponsored cancer prevention and control research throughout the U.S.; apprise people of other NCI-sponsored activities targeted to Native Americans; and, apprise Native people that NCI has career and job opportunities for minorities. The exhibit was sent to different conferences in 1990-1991.

## CANCER PREVENTION AND CONTROL WORKSHOP FOR AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS

The National Cancer Institute's *Cancer Prevention and Control Workshop for American Indian and Alaska Native Populations* was a two-day workshop held in Tucson, Arizona on March 23-24, 1990. The purpose of the workshop was to assist the participant in translating cancer data into culturally sensitive terminology and concepts appropriate for their local tribal community. The two-day workshop included 45 participants from diverse regions of the U.S. Over two-thirds of the participants were enrolled tribal members and over 80% were female. The participants included health care providers, clinicians, and indigenous aids (e.g., Community Health Representatives) in American Indian and Alaska Native reservations, urban clinics, tribal hospitals, and Indian Health Service (IHS) sponsored health care settings. This workshop was one component of the Special Populations Studies Branch's efforts to implement research capacity development for the American Indians and Native Alaskans in addressing their cancer issues.

The agenda included the following topics: cancer "statistics" and "Native Peoples", high risk behaviors, cancer prevention screening and treatment among Native Populations, traditional medicine and cancer, cultural barriers related to cancer prevention, implementing cancer prevention and control in different settings, making educational messages culturally sensitive, small group work with educational materials, making the message understandable and culturally sensitive, making the aid understandable (visual, video, audio), simple messages with audio tapes, small group work with simplifying messages, and examples of culturally sensitive video-tape.

The cancer sites which were highlighted in the workshop were cervical, breast and lung cancer.

Several of the participants of the workshop have since been hired as consultants to assist with developing, concept-testing and/or pretesting cancer education materials designed for Native people.

## **AMERICAN INDIANS AND ALASKA NATIVES CANCER PROGRAM/RESEARCH RESOURCE DIRECTORY**

During 1991, the Network for Cancer Control Research among American Indian and Alaska Native Populations collected information from Native American organizations regarding cancer prevention and control informational materials. Utilized data from that task, the Special Populations Studies Branch initiated the preparation of a resource directory of existing cancer education and/or research programs that are focused on Native Peoples.

The purpose of this directory is to assist Native American researchers or Program Planners in identifying existing materials which may be included in cancer prevention and control research programs or projects.

The directory will include a description of the materials, how the materials originated, were obtained, SMOG literacy level and so on. When feasible a picture of the material will also be included.

The anticipated date of completion for this directory is fall 1993.

# **INTRA-AGENCY AGREEMENT WITH INDIAN HEALTH SERVICE - ALASKA NATIVE AREA - FIVE-YEAR CANCER SURVEILLANCE OF ALASKAN NATIVES** *(February 1989 to January 1994)*

## **Background**

This five-year program of cancer surveillance in Alaska designed to serve the Native American populations through an intra-agency agreement among NCI, the Indian Health Service, and the Arctic Investigations Laboratory of the CDC. In 1989 the Indian Health Service was awarded a contract to collect accurate cancer incidence, mortality and survival data for Alaska Natives. The data was to be entered into the format which meets the criteria and standards of the Surveillance, Epidemiology and End Results (SEER) program of the National Cancer Institute (NCI).

## **Purpose**

The purpose/goals of this agreement were: (1) to maintain active cancer surveillance and document all newly diagnosed Alaska Native patients with invasive cancer since 1969, and in situ (CIN III) cancers starting in 1990; and (2) to collect and computerize detailed information on all cancer patients including demographics, basis of diagnosis, stage, treatment and follow-up.

## **Objectives:**

1. To collect select items of information on all cases of invasive cancer in Alaska Natives who were residents of Alaska at the time of their diagnosis.
2. To computerize the information using a format which meets the criteria and standards of the SEER program of NCI and submit that information periodically to SEER.
3. To document the procedures and techniques used to diagnose cancer and determine the stage and the extent of disease at time of diagnosis.
4. To document the types of therapy used to treat the cancer patient, such as, surgery, radiation, chemotherapy and immunotherapy.
5. To maintain follow-up information on each patient entered in the tumor registry to ascertain their status and if deceased, the cause of death. Any subsequent treatment and recurrence of cancer are recorded as part of the follow-up information.
6. To provide accurate data while maintaining the confidentiality of all medical and personal information in the tumor registry.

## **Statement of Work**

1. For those cancer cases diagnosed among resident Alaskan Natives between January 1, 1969 and December 31, 1983 and which have already been registered, the Agency is to



provide follow-up information for purposes of survival analyses which will include date of last contact if alive and date of death and cause of death as coded on the death certificate if dead.

2. For cancer cases diagnosed among resident Alaskan Natives between January 1, 1984 through December 31, 1988 the Agency shall enter the cases into the Alaskan Native cancer surveillance system.

3. Beginning with cases diagnosed January 1, 1989, forward the Agency shall maintain a cancer surveillance reporting system in the State of Alaska for the purpose of registering all cases of cancer diagnosed among resident Alaskan Natives.

4. The Agency shall collect data in sufficient detail so that each cancer can be classified and coded in accordance with written procedures (e.g., code manuals) specified by the NCI SPSB Program staff.

5. Additional data items to be collected, abstracted, and coded as part of the standardized record format according to written procedures provided by NCI and submitted to NCI include:

- Ethnicity to linguistic subgroup
- Quantum native blood
- Village of birth
- Village of diagnosis
- Use of tobacco products
- Alcohol usage history
- Information on whether cancer was detected by screening

6. The Agency shall collect complete information regarding extent of disease and first course of cancer-directed therapy on all patients diagnosed in 1984 forward.

7. Utilizing all available methodologies, the Agency shall obtain active follow-up on all cases diagnosed in 1969 forward among Alaskan Native residents of Alaska. Reporting and data processing procedures are to be maintained so as to provide current active follow-up on all living cases within a year of the data of diagnosis or the date of last contact, whichever is later.

8. The Agency shall continue to maintain and update a data processing system which will allow processing of all incoming data, perform basic data edits, update patient and tumor specific information, and facilitate preparation of the SEER submission tapes.

9. The Agency shall cooperate with the NCI field staff in its quality control activities.

10. The Agency shall maintain a core staff, including both professional and technical personnel, to carry out specified identified tasks.

11. The Agency shall arrange for 1-2 of its staff members to attend 1 or 2 workshops or meetings of the SEER Program in order to insure that the Agency's staff can implement new codes or procedures, and for the exchange of ideas regarding solutions to problems which arise in tumor registry operations.

12. The Agency shall submit a quarterly progress report during Year 1 of this contract and annual progress reports for years 2 through 5.

13. In all publications resulting from research performed under this contract the Agency shall acknowledge support of the Division of Cancer Prevention and Control, National Cancer Institute, National Institutes of Health, Department of Health and Human Services, under Intra-agency Agreement No. Y02-CN-90666-41.

**INTRA-AGENCY AGREEMENT WITH INDIAN HEALTH SERVICE - TUCSON RESEARCH OFFICE**  
*(July 1989 to June 1993)*

**Background**

The National Indian Health Service (IHS) is mandated to provide health and medical services to about 1.9 million American Indians and Alaska Natives (predominately in the 33 reservation states), and provides the central organizational focus for cancer prevention and control services in this high risk population. The IHS program consists of Tribally and Federally operated hospitals, clinics and health centers as well as an extensive contract health services component. The mission of IHS is to raise the health of Indian people to the highest possible level.

Demand for services from the IHS increased over 29% in last decade, but with little increase in funding. The IHS is promoting the development of a healthy younger Native generation and as a result monies are primarily being used in Maternal Child Health and other types of programs which are likely to prevent diseases and disorders and promote a healthy generation. Cancer primarily occurs in older people.

This IAA allowed IHS to work collaboratively with NCI in research projects to determine how and why cancer survival is so poor among Native Peoples as well as determine the risk factors which are responsible for the rapid rise in cancer among Native Peoples during the last thirty years.

**Purpose**

This IAA was designed to encourage consortia of existing cancer control-related research institutions and relevant regional health agencies to pool their resources in an administrative mechanism that would effectively address cancer control research projects directed towards achieving the year 2000 cancer goals. This Agreement directly supported NCI objectives by (1) providing the impetus for a specialized cancer center consortium, and (2) developing program activities which enhance the goals for cancer prevention and control for special populations at NCI.

This Intra-Agency Agreement between the Indian Health Service (IHS) and the National Cancer Institute (NCI) was intended to provide support for the planning and development of research projects directly related to primary prevention and avoidable mortality. The ultimate goal of this agreement was to bring together the expertise and objectives of the NCI with the service responsibilities of the National IHS. It was further anticipated that this IAA will support the development of specific projects which will provide the experience and data base necessary for the National IHS to eventually apply for a consortium cancer center planning grant.

**Objectives**

The objectives of this Intra-agency Agreement were:

- A. To stimulate cancer prevention and control activities within the National Indian Health Service.
- B. To develop descriptive cancer research projects to be implemented within the Indian Health Service.
- C. To address the cancer control needs of American Indian/Alaska Native populations.

This agreement attempted to bring together the cancer research expertise and objectives of the NCI with the service responsibilities of the National IHS.

#### **The Statement of Work for the Intra-agency agreement (IAA)**

Statement of Work #1: The Agency shall identify, locate, gain access to and develop a working knowledge of existent national and regional data bases containing information on the burden of cancer among American Indian/Alaskan Native populations.

Statement of Work #2: Using the above data bases (and others as the need arises) the Agency shall describe the burden of illness due to cancer in the American Indian and Alaskan Native populations.

Statement of Work #3: Variations in cancer incidence and mortality between various IHS Administrative Areas shall be used to identify areas where there are deficiencies in patterns of care and care seeking behavior. Testable intervention hypotheses shall be generated addressing correctable deficiencies.

Statement of Work #4: Descriptive studies of the prevalence of known behavioral cancer risk factors such as diet, the use of tobacco products, and the use of alcohol shall be conducted in order to provide information on the prevalence of these risk factors in American Indian and Native Alaskan populations.

Statement of Work #5: Descriptive studies of the patterns of care received by American Indian and Alaskan Native populations shall be conducted. Obstacles to early diagnosis and adequate treatment that are attributable to the system of care shall be determined and testable intervention hypotheses shall be generated.

Statement of Work #6: Areas for further study shall be identified with emphasis on design, methods development, and pilot testing of intervention studies of the effectiveness of cancer prevention and control strategies among American Indian and Alaskan Native populations shall be identified.

#### **Examples of Accomplishments from the 1989-1992 NCI-IHS Intra-agency Agreement**

Nine research projects were completed as part of this intra-agency agreement. The IHS publication, "Cancer Incidence in American Indians and Alaska Natives" is an example of one project (excerpt included in Appendix F).

Another project focused on mortality databases to determine racial misclassification. The New Mexico SEER Registry, at the time of database review, contained few errors, only 0.13 percent. However, racial misclassification ranged from 20-40% for the Fred Hutchinson Cancer Research Center and Montana Central Tumor Registry. They also examined found underreporting of Indian race on state death certificates in California, Oklahoma and Washington (the error rates are likely higher in California and Oklahoma which are the two States with the highest number of American Indians according to the 1990 Census). The states which include IHS Areas and were found to NOT have significant problems with racial misclassification at death included Alaska, Albuquerque, Phoenix, Bemidji, and Aberdeen.

The IHS developed, pretested and administered the "IHS Providers' Knowledge-Attitudes-Beliefs-Behaviors (KABB)" survey to 1050 IHS providers (response rate was 70 percent, n=739). Among the findings was that clinicians in six IHS Administrative Areas reported IHS policies as an important barrier to screening mammography (diagnostic mammograms are allowed, but not screening mammograms) on their patients and most did not understand the importance of clinical breast examinations. As a result, provided education is being planned.



# **CHAPTER 11: ADDITIONAL NCI-SUPPORTED NATIVE AMERICAN PROJECTS**

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## **CHAPTER OBJECTIVES:**

- BRIEFLY DESCRIBE ADDITIONAL NCI-SUPPORTED NATIVE AMERICAN PROJECTS
    - ◆ DIVISION OF CANCER PREVENTION AND CONTROL
    - ◆ DIVISION OF CANCER BIOLOGY DIAGNOSIS AND CENTERS
    - ◆ DIVISION OF CANCER ETIOLOGY
- 

## **DIVISION OF CANCER PREVENTION AND CONTROL, NCI**

The Division of Cancer Prevention and Control (DCPC) plans and conducts basic and applied research and development, technology transfer, demonstration, education and information dissemination programs to expedite the use of new information relevant to the prevention, detection, and diagnosis of cancer and the pretreatment evaluation, treatment, rehabilitation, and the continuing care of cancer patients throughout the country. DCPC plans, directs and coordinates the support of research on cancer prevention and control at cancer centers, community hospitals, and through organ systems programs. This Division also coordinates a number of geographically based cancer reporting systems and applies statistical, analytic, and quantitative methods to monitor progress toward cancer control in the United States. DCPC supports cancer research training, clinical education, continuing education and career development in cancer prevention and control. The Division administers programs for the support of construction, alteration, renovation, and equipping of extramural research facilities. DCPC coordinates program activities with other Divisions, Institutes, or federal and state agencies and establishes liaisons with professional and voluntary health agencies, cancer centers, labor organizations, cancer organizations and trade associations.

## **CANCER CONTROL SCIENCE PROGRAM**

The Cancer Control Science Program is one of four major programs included within the Division of Cancer Prevention and Control. The goal of the Division of Cancer Prevention and Control (DCPC) is to achieve significant reductions in cancer incidence, mortality, and morbidity, with a concomitant increase in cancer survival. The Cancer Control Science Program (CCSP) seeks to further this goal by advancing the science and application of cancer prevention and control. The program's efforts are directed toward administering intramural research initiatives to evaluate the efficiency and efficacy of cancer control interventions; monitoring basic, clinical, behavioral, and health education research to identify new intervention strategies; and supporting extramural research programs to address issues such as cancer control problems among particular populations, worksite cancer control activities, and modification of smoking and tobacco use. Each of the CCSP's four research branches

attempts to improve services and interventions by focusing on different aspects of cancer prevention and control.

#### **PREVENTION AND CONTROL EXTRAMURAL RESEARCH BRANCH**

**Rationale:** The development of a large, multidisciplinary research base in cancer prevention and control interventions is central to improving methods, technology, and services as well as ultimately to reducing cancer-related morbidity and mortality.

The newly established Prevention and Control Extramural Research Branch (PCERB) supports primary prevention intervention research as well as investigator-initiated grants. It administers an extramural applied research program that investigates intervention methods to modify primary prevention risk factors such as the use of tobacco and alcohol, diet and nutrition, and occupational and sun exposure. For example, the Community Intervention Trial for Smoking Cessation (COMMIT) is a randomized community-based trial that is testing a protocol of smoking cessation strategies aimed primarily at heavy smokers. The study involves more than 2 million people in the United States and Canada and will provide a model to communities around the country.

The PCERB also fosters and supports Phase 2 through Phase 5 prevention and control investigator-initiated grants. These awards include large multi-study projects such as the Cancer Prevention Research Units and the Cancer Control Science Program as well as single intervention studies. Additionally, the PCERB uses small grants and related mechanisms to develop a cadre of highly qualified professionals who can perform rigorous cancer prevention and control intervention research.



### **The American Stop Smoking Intervention Study for Study for Cancer Prevention (ASSIST)**

The American Stop Smoking Intervention Study for Cancer Prevention (ASSIST), a collaborative effort led by the National Cancer Institute and the American Cancer Society, is a demonstration project designed to significantly reduce smoking prevalence. ASSIST will apply the best available strategies to prevent and control tobacco use in order to significantly accelerate the current downward trends, thereby reducing the number and rate of tobacco-related cancers. Through ASSIST, comprehensive tobacco-use control coalitions are being developed in 17 States. These coalitions will be led by State health departments and will include voluntary health agencies and other community organizations with the capacity to reach large numbers of smokers. Targeted populations are those for which smoking prevalence rates are elevated relative to the majority population and groups that have displayed slower rates of decline (e.g., women, the medically underserved, the less educated, and several ethnic minority populations). Through ASSIST, 17 sites have been funded for a 24-month planning period beginning October 1991. The five-year intervention phase will begin in October 1993 and continue through 1998. Native American women will be targeted in a number of ASSIST sites, notably in New Mexico.

## **PUBLIC HEALTH APPLICATIONS RESEARCH BRANCH**

**Rationale:** The public health system, including Federal, State, and local agencies, is critical to the successful delivery of tested cancer prevention and control interventions to large numbers of people. These agencies constitute a valuable national infrastructure for reaching not only populations that otherwise would be underserved but also the entire population of a State or locality.

Formerly known as the Cancer Control Applications Branch, The Public Health Applications Research Branch (PHARB) builds public health capacity for cancer control interventions and supports public health demonstration projects. A major activity of this branch is the American Stop Smoking Intervention Study (ASSIST). This large scale demonstration program, now in its early stage, will disseminate the results of the NCI's smoking and tobacco programs. The NCI, The American Cancer Society, and other voluntary organizations will work jointly through public health agencies and regional coalitions to conduct interventions and activities at ASSIST sites in up to 20 geographical areas throughout the United States.

The PHARB also administers applications of primary and secondary interventions in health care settings. For example, the branch is developing training courses that will help physicians and dentists around the country counsel their patients on smoking cessation. The Data-Based Intervention Research for Public Health Agencies initiative provides grants that help public health agencies build their capacity to undertake programs in cancer prevention and control. The PHARB also is responsible for health education initiatives, which currently include work-site interventions that address nutrition, cancer screening, and tobacco control as well as breast cancer screening initiatives that are aimed at improving the utilization of mammography and other types of breast examination.

### **Data-based Intervention Research Projects which are focused on American Indians**

The goal of the Data-based Intervention Research (DBIR) Program is to work with state and local health departments to build the foundation for on-going programs that will translate cancer prevention and treatment science into practice across the United States. Currently, 21 states and the District of Columbia are supported by the DBIR Program. Initially, six states received awards. Two years later, in 1989, eight additional awards were made and in 1990 eight more states received funding under the DBIR Program.

Under these awards, recipients analyze available data to develop state cancer control programs and begin the implementation and evaluation of high priority cancer control interventions that meet the unique needs of each state. Among the major advantages for participants in the DBIR program, are opportunities to share and benefit from the experiences of other states that are also developing and implementing cancer control programs.

Three of the twenty-two projects include American Indians as the target population, Nebraska, North Dakota and Alaska. The Nebraska DBIR is on cervical cancer detection and the North Dakota DBIR is on tobacco use reduction, breast cancer detection, and cervical cancer detection. In 1992 the Alaska project began to develop a state cancer control plan which will include information about cancer and Alaska Natives and will serve as the basis for targeting cancer control interventions.

## NCI Cervical Cancer Video for American Indian Women

"Taking Control of Your Health: The Pap Test and Cervical Cancer" is a remake of an intervention product developed by the Nebraska Department of Health under a grant from NCI's Data-based Intervention Research Project. The original video was tailored for women of the Omaha and Winnebago tribes of Nebraska. Research conducted among one hundred Indigenous women in six geographically diverse regions of the U.S., as well as during the 1991 "Wellness and Women II Conference" showed the potential of this video to influence a wide range of Native American women. Findings underscored the need for and value of the message being communicated but also identified some possible areas for improvement.

The NCI Office of Cancer Communication collaborated with the PHARB and SPSB staff and with the Omaha Nation and the Nebraska Department of Health and other community partners, to incorporate the research recommendations and revise the video. Specifics regarding the video follow:

Title:	"Taking Control of Your Health: The Pap Test and Cervical Cancer"
Target Population:	American Indian women
Length:	9 minutes
Equipment:	VHS machine and monitor
Purpose:	To motivate Indigenous women to have an annual Pap smear.
Long range goal:	<ul style="list-style-type: none"> <li>■ To increase the number of Indian women who receive annual Pap smears.</li> <li>■ Improve cervical cancer survival rates among American Indian women.</li> </ul>

### *Description:*

"Taking Control of Your Health: The Pap Test and Cervical Cancer" is a nine minute video which was designed to motivate Indigenous women to have an annual Pap smear. It includes an overview of the cervical cancer problem among Indian women, explanation of the Pap test, cervical cancer screening recommendations, ways to protect yourself from cervical cancer, and advice on obtaining additional information about Pap tests.

The video incorporates various Indigenous women and Native ceremonies. Indigenous medical professionals and patients are highlighted. Well-known Native musician, Joanne Shenandoah, and Native American communications specialist, Marisa Arbona, together wrote and produced an emotionally-empowering song, reinforcing the important health message of taking care of yourself.

*Dissemination*

Approximately 200 advance copies of the video were disseminated during the "Wellness and Women IV" meeting in Phoenix, Arizona during February 1993. During the meeting, Native American leaders were provided a special showing of the tape and asked for their suggestions regarding its dissemination. Their recommendations were incorporated into a distribution plan which focuses on disseminating the video to American Indian intermediaries (including advocacy groups, women leaders and health professionals), as well as tribal media and media outlets serving American Indian communities. The video will be accompanied by a booklet providing additional background on the cervical cancer problem and presenting ideas for the video in Indian communities. The dissemination plan is scheduled for implementation during the summer of 1993.

## **Minnesota State Department of Health American Indian Cervical Cancer Screening Research Project**

The purpose of the Minnesota Department of Health, "Increasing Cancer Screening among Underserved Women" (1989-1995) is to design and evaluate two approaches to increase breast and cervical cancer screening rates among women who are predominantly indigent, elderly and/or Native American, 40 years and older. Focus groups were conducted (1) with women who kept mammography appointments; (2) with women who had scheduled, but not kept, mammogram appointments; and (3) with women who had refused to have mammograms. Approximately 400 Native American women will be randomized as participants in the two approaches to increase screening rates.

## The NCI Low Literacy Nutrition Education Materials for Native Americans

The National Cancer Institute, Cancer Control Science Program initiated a project on *Low Literacy Nutrition Education Materials for Specific Underserved/Ethnic Populations* in December 1989. The following populations were targeted, based on the incidence and prevalence of certain cancers within their midst, as well as their need for low literacy nutrition education materials: American Indians, Alaska Natives, Native Hawaiians, Chinese, Filipinos, Vietnamese, Hispanics, African Americans and low literate whites. A variety of culturally sensitive nutrition materials are being developed to address the low literate segments of these groups.

Two adjunct documents are also being produced to help health professionals work more effectively with these underserved/ethnic populations. The first, *Nutrition in Primary Care: How to Help Your Patients Improve Their Eating Habits*, is a manual designed to provide primary care physicians with information and tools needed to incorporate nutrition advice into their office practice. The second is a handbook, *Teaching Your Ethnic Patients*, developed to help health professionals work more effectively with people from various underserved/ethnic populations.

The developmental process for the culturally sensitive materials involved several steps. Representatives from each ethnic or low literacy group were invited to serve as members of a working group. The purpose of the working group was to identify the types of nutrition education materials and messages which were most needed and most appropriate for their population. Based on recommendations made by this group, preliminary materials were drafted, reviewed in informal concept-testing, and revised. Specific "learner verification" questionnaires were developed for each piece of material to be used in formal "pretesting".

To illustrate the complete process, the following summary describes how the American Indian materials were developed and pretested.

### *Lists of Participants in this Project*

Three groups of individuals had major roles in the development, revision, and pretesting of American Indian low literacy nutrition education materials.

- **The NCI Low Literacy Nutrition Internal Group.**

The NCI Low Literacy Nutrition Internal Group was comprised of people from NCI, or on contract with NCI, who were directly responsible for the project and had expertise in the areas of medicine, literacy, and/or nutrition education.

- **The American Indian Working Group.**

The American Indian Working Group includes health care professionals who work closely with American Indian populations in diverse regions of the country. Members of the original Working Group participated in a workshop on developing low literacy nutrition materials during December 1989. Following that workshop, additional participants who have had experience developing culturally sensitive

education materials for American Indian tribal communities were invited to serve as members of the American Indian Working Group.

- **The Pretesters.**

The pretesters were selected based upon the following criteria:

1. Of American Indian descent
2. Expressed interest in the area of American Indian nutrition
3. Experience developing educational materials
4. One of the following:
  - a. Participant in the 1990 NCI-sponsored Workshop on Low Literacy and Cancer Prevention and Control in American Indians
  - b. Experience developing low literacy educational materials for American Indians

Collectively, the pretesters represent (a) different tribal affiliations and (b) different geographic regions. Two phases of pretesting occurred. The initial pretest was of seven drafts of materials and was implemented in urban, rural, and Reservation and/or Rancheria settings during the month of September 1991. An attempt was made to include both sexes as interviewers and as interviewees.

#### **A Brief History of the Development of the American Indian Materials**

The *American Indian Working Group* made recommendations for the development and revision of nutrition education materials. Based upon those recommendations, the draft materials were developed by Charon Asetoyer, Pintip Chotibut, and Corrine Tanon, all of whom are American Indian.

The draft materials were critiqued and revised by the *NCI Low Literacy Nutrition Internal Group* and the Program Director of the Native American Cancer Control Program within the Special Populations Studies Branch CCSP, DCPC, NCI. Pretesters were scheduled to interview American Indian men and women utilizing learner verification questionnaires specifically designed for each educational material during the month of September, 1991.

#### *The Materials*

Initially there were a total of seven pieces of draft materials to be pretested. The pieces were organized into the following five groups:

- Traditional Foods Can be Healthy (*pamphlet*)
- Less Fat is Easy (*booklet*)
- Why All the Talk About Fiber (*booklet*)
- Tear-off Sheets and/or posters
  - Healthy Choices on the Road (*tear-off sheet*)
  - Traditional Foods can be Healthy (*tear-off sheet*)
  - Making Fry Bread More Healthy (*tear-off sheet*)
- Video Story Board (*pictorial and script story board*)



Four of the five groups were pretested during the latter part of fiscal year 1991. The video story board was disseminated for pretesting during the fall of 1991.

### *The Pretesting Process*

The pretesters selected American Indians from their local tribal community of both sexes and of varying ages and educational levels to participate in the pretesting interview process. Approximately twenty interviews were conducted for each group of materials, which is a total of 100 interviews within each pretesting site. The pretests were administered in a one-to-one interview format using the "Learner Verification Interview" questionnaire which had been designed for the group of materials being pretested. The American Indian participant was asked to read and examine one group of materials and then to respond to the questions specific to that educational item. Approximately 15-20 minutes were required to conduct the interviews and complete the questionnaires for each group of materials.

The pretesters completed the interview questionnaires as well as the "Questionnaire for Interviewers". The originals of the completed interview questionnaires were mailed to the low literacy contractors for analysis. Recommendations for final revision were submitted to the Doaks, literacy experts associated with the project.

Based upon the initial round of pretesting, the draft materials were consolidated and revised. For example, tear-off sheets were incorporated with the "Less Fat is Easy" booklet. The pamphlet "Traditional Foods Can Be Healthy" was dropped (subsequently, the Special Populations Studies Branch revised, pretested and produced this pamphlet independently). The outcome of the first round of pretesting was the further development of two booklets:

- Less Fat is Easy (renamed: Why All The Talk About Fat)
- Why All the Talk About Fiber

After these two booklets were revised, they underwent a second round of pretesting in the spring of 1992, using one-on-one interviews. The revised booklet "Why All the Talk About Fat" was tested with a total of 63 people (43 females, 20 males), representing 25 tribes. The revised booklet "Why All the Talk About Fiber" was tested with 55 people (35 females, 20 males), representing 24 tribes. Both booklets were tested in Arizona, Oklahoma, California, Nevada, North Carolina and Washington State. Final changes were made to the booklets based on the pretest results.

## **NATIVE AMERICAN CANCER PROJECTS SPONSORED BY DIVISIONS OTHER THAN DCPC**

### **DIVISION OF CANCER BIOLOGY, DIAGNOSIS, AND CENTERS**

#### **Background**

The Division of Cancer Biology, Diagnosis, and Centers (DCBDC) of the National Cancer Institute (NCI) is responsible for planning, coordinating and directing a national and international program of basic research in cancer biology and diagnosis. Intramural studies are performed in laboratories and clinics on the NIH Bethesda campus and at the Frederick Cancer Research and Development Center. Extramural research support is provided to universities, private research institutions, and cancer centers through various funding mechanisms including traditional research project grants, program project grants, center support grants, contracts, and cooperative agreements, or by the transfer of funds to other Federal agencies. The results of these studies are integrated with results obtained by other institutions throughout the world.

In addition, the Division plans and administers an extramural program which supports and fosters cancer research training in order to assure the continuing existence of a national cadre of highly qualified individuals to work in the fields of cancer research, treatment, prevention, and control. DCBDC also administers a program of support for the construction, alteration, renovation, and equipping of extramural research facilities which house cancer research activities. The Division's Laboratory of Pathology provides surgical pathology and postmortem services to the NIH Clinical Center and the clinical programs of all of the Institutes and NCI Divisions. The DCBDC also bears responsibility for the Advanced Scientific Computing Laboratory (ASCL) in Frederick, MD, the nation's first supercomputer facility solely dedicated to biomedical research.

Internationally, the Division of Cancer Biology, Diagnosis, and Centers has entered into agreements through contracts and formal arrangements with the USSR, Japan, France and other foreign governments to effect cooperation among these nations in the field of cancer treatment. The Division consists of four major organizational components: Office of the Director; Intramural Research Program (IRP); Extramural Research Program (ERP); and Centers, Training, and Resources Program (CTRP). The Director, DCBDC, serves as the Scientific Director.

## NCI Native American Training Events, "Native American Training Opportunities: Strategies for the Future"

### Background

The *Senate Appropriations Report for Fiscal Year 1992* urged "NCI to organize four research training events which emphasize development of technical skills, training in research methodology and evaluation, and proposal development in fiscal year 1992".<sup>1</sup> Originally, NCI staff organized four regional meetings, however, due to travel budgetary constraints, the four meetings were compiled into one major training event held in Bethesda, Maryland. The Division of Cancer Biology Diagnosis and Centers (DCBDC) and the Division of Cancer Prevention and Control (DCPC) of the National Cancer Institute collaborated on planning and implementing a major training event and a series of workshops that would reach Native Americans (e.g., American Indians, Alaska Natives, Native Hawaiians, and American Samoan) from August 30 to September 1, 1992.

### Meeting Information

- Meeting Title: Native American Training Opportunities: Strategies for the Future
- Dates: August 30 - September 1, 1992
- Location: Holiday Inn, Bethesda, Maryland
- Purpose of the meeting: Provide an **opportunity** for Native Americans and NCI-designated Cancer Centers to interact with one another, discuss their own group's cancer research priorities, and identify *potential* collaborative efforts (both short and long term).
- Goals:
  1. Increase the number of Native Americans who participate in NCI-sponsored basic, clinical and prevention and control research.
  2. Expand cancer research and education activities that will reduce cancer incidence and mortality in Native American populations.
  3. Increase the number of Native Americans who are principal investigators and co-investigators on research projects sponsored by the NCI.

### Selection of Participants

A variety of sources submitted names for potential participants in the August 31-September 1 Native American Training Event, including, but not limited to the following:

1. Four Cancer Centers were requested to submit names of interested participants from their respective areas (e.g., Arizona, Hawaii, North Carolina, Washington, Minnesota)
2. The *Network for Cancer Control Research among American Indian and Alaska Native Populations* was asked to recommend participants.

3. The American Indian Alaska Native Caucus, as recognized by the American Public Health Association, included a general solicitation in their Winter 1992 Newsletter. In addition, Caucus representatives from different regions (NY, WA, AZ, AK) were asked for their suggestions.

4. Vince Cairoli from the Cancer Training Branch made presentations regarding training opportunities and provided an overview of the August 31-September 1 meeting to the following meetings:

- Avoidable Mortality Cancer Research Interventions among Native Americans Grantee Meeting (April 9, 1992)
- Primary Prevention Cancer Research Interventions among American Indians Grantee Meeting (April 27, 1992)
- *The Network for Cancer Control Research among American Indian and Alaska Native Populations* Spring meeting (May 1, 1992)

Requests for suggestions for participants followed each presentation.

5. Indian Health Service professionals were asked for their suggestions (May 1992)

6. Sign-up Sheets which had been disseminated during Native American meetings from 1990-1992 included a check list of projects/activities people would like to receive further information. Respondents who identified their interest in training opportunities and returned the forms to the Native American Cancer Control Program, SPSB, CCSP, DCPC, NCI were sent an invitation to participate. Examples of meetings where the sign-up sheets were disseminated include the following:

- American Indian Professors Meeting
- Association of American Indian Physicians
- Wellness and Women (Native Women)
- Multi-ethnic Health Promotion Conference in California
- American Public Health Association

7. The Program Director of the Native American Cancer Control Program reviewed her personal database for potential participants.

The meeting was limited to one hundred participants which met together for the initial one and one-half days and then separated into one of five regional break-out groups. The NCI invited Natives Americans from the continental United States, Alaska, Hawaii and American Samoa who (1) had the most advanced experience in prevention and control research; (2) were leaders of Native American communities who could contribute cultural perspectives and sensitivities to the development of effective strategies and who could serve as critical gatekeepers in helping to implement these strategies; and (3) were involved in recruiting Native Americans into training and fellowship programs. Final selection included one hundred and six scientific and community representatives (90 indigenous Peoples and 16 non-Natives).

### **NCI-designated Cancer Centers**

The main purpose of the Cancer Centers Program of the National Cancer Institute is to foster the development, productivity and stability of the *research* activities of the cancer centers, specifically through Cancer Center Support Grants; however, NCI-designated Comprehensive Cancer Centers conduct a wide range of activities that depend on a broad

spectrum of Federal and non-Federal funding sources, such as research grants, contracts, prevention and control grants, training grants, education grants, cooperative agreements, State awards, institutional funds and private donations.<sup>2</sup> NCI supports approximately 56 centers throughout the United States such as basic centers, clinical centers, or comprehensive centers. Twenty-eight of these are "comprehensive cancer centers" which means that they provide the following: state-of-the-art care and service, research, linkage of research to patients and populations, education and training of biomedical researchers and health care professionals, public information services, and community service and outreach.

Participating Comprehensive Cancer Centers included the following: Arizona Cancer Center, University of Michigan Cancer Center, Mayo Comprehensive Cancer Center, Roswell Park Cancer Institute, Comprehensive Cancer Center Wake Forest University, Fred Hutchinson Cancer Research Center, and the University of Wisconsin Comprehensive Cancer Center.

In addition, Institutions which had P20 Cancer Center Support Grants or are Clinical Centers and were located in geographic regions which have a substantial number of Native Americans were also invited to participate in this training event. This included the University of Colorado Cancer Center, University of New Mexico Cancer Center, and the Cancer Research Center of Hawaii.

### *Agenda*

Sunday evening, August 30, 1992, was a reception to provide an opportunity for participants and NCI staff to casually interact prior to the Meeting. Representatives from each Native population (American Indian, Alaska Native, Native Hawaiian, and American Samoan) provided a few moments of entertainment (e.g., singing, dancing) during the reception.

The Monday, August 31 agenda (8:00 a.m. - 9:00 p.m.) included the following:

- Welcome

- Greetings (participants from each Native population provided a traditional Native greeting and welcome to all present)

- The Mission of the National Cancer Institute

- Purpose and Objectives (of this meeting)

- Cancer Among American Indians

- Cancer Prevention and Control Research in the NCI

- NCI-sponsored Native American Research Projects and/or Activities

- Cancer Among American Samoans

- NCI-sponsored Training and Education Opportunities available to Native Americans

- Cancer among Native Hawaiians

- NCI-sponsored Research Opportunities

- Cancer Among Alaska Natives

- Overview of the Grants Application Process

- Common Problems with Native American Applications

- Suggestions for Improving Native American Grant Applications

Tuesday, September 1 agenda (8:00 a.m. to 9:00 a.m.) included the following:

- Native Greetings

### Opening Remarks

New Mexico Tumor Registry and Accurate Racial Classification

On-going Cervical Cancer Studies and Southwestern Indian Women

September 1 Breakout Groups' Agenda (9:00 a.m. - 4:00 p.m.) included the following:

Potential of Regional Cancer Centers to work cooperatively with Native Americans in the development of education, training and research programs

Perspectives for the Future: Recommendations of developing effective programs with native Americans

Perspectives of Native Americans in Addressing the Problems of Cancer in their communities through the development of education, training and research programs with Cancer Centers.

The collaborative development of short (1-3 year) and long-term (10 years) strategies in cancer education, training, and research involving Native Americans, Cancer Centers and the NCI

### *Breakout Group Summaries*

Ten NCI-designated Cancer Centers indicated an interest or need to learn more about Native Americans in order to more effectively include indigenous peoples in their outreach efforts as is required of a "comprehensive cancer center". Those ten Centers were "grouped" to create five "regions" or breakout groups. Approximately twenty Native Americans were recruited from each of those five "regions" as participants. The groups were organized to provide the opportunity for a small group of people who lived in relatively "close" distance from one another to discuss strategies for future collaboration on education, training or research projects. The groups were not considered to be "homogenous". Participants were recognized as heterogeneous peoples. For example, the Minnesota/Wisconsin Cancer Centers include American Indians from Montana (Blackfoot tribe), Texas (Kiowa), and South Dakota (Oglala Sioux). These tribes are very different from one another. Likewise, the Hawaii Cancer Center includes both Native Hawaiians and American Samoans and these populations are extremely different from one another. NCI was aware of and acknowledged the heterogeneity of these diverse cultures.

Strategies for the future focused on (1) education, (2) training; and (3) research. These terms are used differently by the government than they are used by non-government employees. Please note the descriptions of the government's terminology for these terms.

*Education:* The process of transferring state-of-the-art knowledge about cancer to people. This can be directed toward health care personnel or to lay people. It is done to ensure that every community derives the maximum benefit from what is known about cancer prevention, cancer detection, cancer diagnosis, and cancer treatment.

*Training:* The process of developing and increasing the research skills of individuals as preparation to conduct independent research in cancer prevention, cancer control, cancer detection, cancer diagnosis, cancer treatment, and basic cancer biology.

*Research:* Developing new knowledge and technology or new methods for transferring existing knowledge. This is done through experimentation in the laboratory, with patients or individuals or with populations.

Each breakout group included a moderator and note-taker who were NCI staff. Participants were also asked to take notes and submit those to NCI staff for inclusion in the breakout summary. Participants suggested that the summary not be a detailed lengthy report, but to include bullets with highlighted information. In compliance with that suggestion, NCI staff attempted to clearly identify issues and suggestions by organizing the participants' and note-takers' summary information into chart format. Each breakout group summary includes four charts: (1) general issues, (2) education issues, (3) training issues, and (4) research issues. The first column described issues which were generated during the meeting from any participant. The second column included suggestions from the group. The third column was for additional input from NCI staff. Participants and NCI staff who participated in the meeting were asked to review and/or correct the summary chart.

An example of the summary chart from the Southwest Regional Breakout Group follows. The Summary Charts were sent to each regional participant for critique. Based upon suggestions received, the summaries were revised. Final drafts of all five summaries are scheduled to be completed during the summer of 1993.

#### *Next Steps*

The Cancer Centers and Native American groups were to continue collaborating with one another to accomplish tasks which were identified as priorities within that respective region/breakout group. The NCI will continue to collaborate with each region to explore additional approaches that will further contribute to the solutions of short term and long term objectives. The September meeting was only a beginning. Successes in the future depend upon continued commitment to work with each other and maintain a regular dialogue.

**AZ/CO/NM BREAKOUT GROUP**

Summary based upon Notes received from Participants  
June 9, 1993 Draft

**I. GENERAL/"ALL-ENCOMPASSING" ISSUES AND SUGGESTIONS**

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
<p>Communication: must establish relationship between the Native populations and researchers <i>prior</i> to collaborating on any research, training or educational efforts. Need to develop rapport, trust and a relationship first.</p>	<p>Need to identify key people from Native population and from the Cancer Centers to meet together and become comfortable with one another's communication patterns, goals and so on. Need to ask Native communities what their needs are rather than telling them what others "can do for them".</p>	<p>Schedule meetings in both the Native settings as well as the Cancer Centers to allow for additional informal interactions with others from that setting.</p>
<p>Native Peoples are asked the same questions by different federal agencies (e.g., NCI, NHLBI, IHS, NCHS, CDC). Why don't the agencies share the responses rather than consuming Native Peoples' time and money and continually reinventing the wheel.</p>	<p>Many questionnaires have been done already. Is there some way of sharing the information from these instruments for future studies? Some government research is a duplication of University and/or tribal research. Agencies should check with Tribal Health Departments to determine what type of research has been done with the specific tribe and/or reservation.</p>	<p>There needs to be some type of trans-NIH as well as trans-DHHS communication. In addition, a collaborative effort which would focus on life styles which affect a variety of diseases rather than being so disease-specific is needed.</p>



## I. GENERAL/"ALL-ENCOMPASSING" ISSUES AND SUGGESTIONS

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
The government starts projects which are of interest to Native Peoples, but these are rarely completed, or if they are finished, they are not disseminated to the populations who could benefit from the findings.	It is important to keep Native communities informed during all stages of a study. After the completion of a study there is a need to share results and implication of the study with Native Communities.	Bureaucratic shifting of priorities is a series of difficult challenges which staff attempt to overcome. NCI staff are aware of the problem, and welcome <i>feasible</i> , efficient solutions to this issue.
The institutes frequently make culturally inappropriate decisions which have implications for indigenous peoples.	Need to have indigenous peoples on Advisory and Review Committees to the federal agencies. Present research proposal to Tribal Health Dept. and/or tribal council.	NCI staff will forward letters of such interest and the resumes of people who would be interested in such activities.
Rural Native American doctors and health care workers feel isolated from others in their profession. Because of the lack of resources, i.e. staff, etc., the priority for the rural doctors becomes provision of medical services, and not research. Segregation exists now.	Bring health care workers in to Cancer Centers from time to time for interaction, workshops, further training, and integration within the larger system, to help relieve the feeling of isolation. Also, the distribution of a list of all researchers, research topic and location of research to tribal health depts. and to researchers would keep everyone informed as to who is conducting research and where. This would keep the local health care workers informed as to what is being done locally.	Rural Native American health care workers would be included on mailing list from Cancer Centers which provides updated information, notification of meetings, RFA's etc.

**I. GENERAL/"ALL-ENCOMPASSING" ISSUES AND SUGGESTIONS**

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
Problem of perception of cancer by Native Americans.	Develop culturally appropriate education materials, or be aware of how to access such material for each tribe.	The Office of Cancer Communication now has an individual who will be responsible for future Native American informational materials: Ellen Eisner (301/402-3304)
Traditional medicine men and women need to be involved in the process of healing, and recaptured as healers by Western medicine.	Recognize the of contributions of traditional medicine. Traditional healers as teachers and mentors for Native American students can help ease the transition between two worlds, and teach holistic medicine.	NIH now has a new position on "Alternative Medicine". Joseph Jacobs, M.D. (St Regis Mohawk Tribe) was appointed to that position this winter.

## II. EDUCATIONAL ISSUES AND SUGGESTIONS

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
Educational and training programs are not accessible to Native Americans.	Centers play a bigger role and should be accountable for showing they have put forth a good effort to recruit and maintain Native participants ("good faith effort") Need for community outreach by cancer centers, particularly for training, etc. that would benefit the Native populations.	Supplemental funding may be available to Cancer Centers for including Native Americans within educational or training programs.  Identify "teams" comprised of both Native Peoples and Cancer Centers on specific tasks, e.g., recruitment strategies, mentorship
There is need for mentors to help young Native students overcome feelings of cultural isolation, and so on.	Cancer Centers are interested in supplementing the professional staff with qualified Native Americans. With such people available, Indian students who participate in Cancer Center projects would have access to mentorship. Students should not be sent too far from their own environment to study.	Perhaps successful "Centers of Excellence for American Indian Medical Education" such as University of Minnesota-Duluth can be used as models and implemented in other settings.

### III. TRAINING ISSUES AND SUGGESTIONS

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
How to identify potentially good students?	Look at Native American Community Colleges and involve them. Students could be trained at Cancer Centers <u>IF</u> the Center has a good program, and if the center expresses a commitment to train Native American students.	Since some groups have had success identifying potential candidates in their indigenous populations, perhaps ask them for copies of the eligibility criteria (e.g., American Indian Science and Engineering Society, University of Minnesota-Duluth Student Research Apprentice Program).

## IV. RESEARCH ISSUES AND SUGGESTIONS

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
Survey questionnaires: need access to culturally appropriate survey instruments	<p>Need to have a directory which identifies existing instruments, on-going research, and materials available to any interested parties. The directory needs to include a list of each piece of material (e.g., videos, educational materials, questionnaire), the name, address, phone number and fax of the contact person, as well as a description of the purpose of the item, the target population for whom the material was developed, length, cost (if any) and so on.</p> <p>A directory of people who have implemented cancer research projects, with some information on the projects (at least titles), among Native American populations would be of assistance.</p> <p>A central clearinghouse for such information would be very appropriate.</p>	<p>NCI has proposed a similar type of "resource" directory but it has not received approval yet.</p> <p>The Cancer Centers and Tribal Peoples may consider collaborating on the preparation of a regional directory which also includes the names of people interested in becoming involved in future research efforts.</p>
Need to have Native principal investigators.	Need to have set aside funds for inexperienced Native researchers.	Other institutions (which do not have <i>research</i> as its primary mission, as does the NCI) have implemented this

## IV. RESEARCH ISSUES AND SUGGESTIONS

Issues	Suggestions from the Group	Suggestions from NCI Staff subsequent to the Meeting
<p>Research projects are reviewed by people who are unfamiliar with Native Peoples' lifestyle, access to care, cultural practices and so on. They do not understand.</p>	<p>Need to have Native Americans included on the Research application review panels.</p>	<p>strategy with controversial results. It is a short term solution and doesn't help the person learn how to compete within the actual system. Set aside monies are very political. If that were the primary way to obtain funding, the Native researcher continues to be inexperienced within the system.</p> <p>NCI staff can assist with this if notified <i>prior</i> to submission of an application. For example, if Principal Investigator notifies NCI staff that their applications include cultural issues which require that members of the review panel must be informed of to appropriately evaluate the merit of the application, NCI staff can formally notify the Division of Grants Management and suggest potential members for the review panel.</p> <p>The SPSB is in the process of recruiting potential Native American grant reviewers. NCI staff will submit letters and the resumes of people who would be interested in being included in the pool of reviewers.</p>

## Cancer in Indian Country

During 1991, the *Network for Cancer Control Research among American Indian and Alaska Native Populations* identified the need for a cancer conference for Indigenous Peoples. Dr. Jenny Joe, Director of the Native American Research and Training Center, University of Arizona, with assistance from other Network members, developed and submitted the application. The application was awarded as an "R13" by the National Cancer Institute. The "R13" Conference Grant mechanism is designed to support national or international meetings, conferences, and workshops that are of value in promoting the goals of the national cancer effort.

The specific goal of the September 15-17, 1992 national conference, "Cancer in Indian Country" was to address cancer research and prevention among American Indians and Alaska Natives. The conference provided information and updates for researchers, clinicians, service providers, traditional healers, and tribal health leaders on cancer prevention, control and treatment.

The conference was held in Rapid City, South Dakota because of the high rates of cancer mortality in this region and the need to create an awareness of this problem among the various tribes there. The South Dakota location is in the heartland of Indian Country for tribes in the Dakotas, Minnesota, Montana, Wyoming and northern Colorado.

The staff from the Black Hills Training Center, an IHS facility in Rapid City, assisted with the local logistics of the conference. Over 100 people participated in the conference. Conference Proceedings are tentatively scheduled to be published in fall 1993.

### *Meeting Information*

Title: Cancer in Indian Country

Dates: September 15-17, 1992

Location: Howard Johnson Convention Center, Rapid City, South Dakota

Purpose: To provide updates on the scope of the problems of cancer, treatments, and prevention and control for new researchers, service providers, and tribal health leaders; to compare with other minority populations, national and regional cancer data on American Indians and Alaska Natives and to explore implications this data has for cancer prevention and control in this populations; explore ways that western medicine and traditional Indian medicine can work together in cancer prevention and control; to identify and present culturally-relevant innovative intervention and prevention models in poster sessions, panels, and workshops; to make abstracts and a current bibliography on cancer in American Indians and Alaska Natives available to all registrants; and to produce a proceedings in form of a monograph, from selected papers and presentations that will serve as reference for researchers and services providers.

## *Agenda*

Tuesday, September 15 (Day 01) included the opening session, welcome ceremonies, keynote address (Cancer in Indian Country - by James W. Hampton, M.D.), Lakota Medicine and Cancer, Tribal Tobacco Policy, Epidemiological Picture and Regional Differences; What more Can I Do (video). The poster sessions included Cancer Data Linkage (IHS with MCTR); Cancer Incidence and Survival among American Indians in Montana: Results from a Data Linkage Effort; Reducing Cancer Risks among Native American Youth in the Northeast; and Native American Mammography.

Wednesday, September 16 (Day 02) included announcements, keynote address, (Year 2000: Reducing Cancer in Special Populations - by Dr. Harold Freeman, M.D.), Innovations in Cancer Prevention; Cancer Survivors and Hospice Care and Concurrent Workshops. The Workshop topics were Health Beliefs about Cancer Causation among Luiseno Indians, Research Gaps, Approaches to Cancer Screening in Indian Communities; Cervical Cancer in Alaska Natives, Cervical Cancer Screening among Pueblo Indian Women at Albuquerque, Cancer Mortality Data, Pathology of Breast, Cervical, and Lung Cancers, and Cancer Incidence and Survival among American Indians in Montana. A Pow Wow was held that evening and Health Exhibits were available to peruse.

Thursday, September 17 (Day 03) included the keynote address (Cancer Research with Special Populations - by Claudia R. Baquet, M.D.), NCI's Native American Cancer Control Projects and Activities, and Conference Summary.



## **Conference on Careers in Cancer Medicine Research for American Indian Youth**

### ***Background***

This conference was initiated by Dr. Alan Rabson, Director of the Division of Cancer Biology, Diagnosis, and Centers, NCI. The conference was organized and implemented by the Native American Research and Training Center (NARTC) of the University of Arizona.

### ***Meeting Information***

**Title:** Conference on Careers in Cancer Medicine Research for American Indian Youth

**Dates:** December 2-4, 1992

**Location:** Tucson, Arizona

**Purpose:** To encourage Native American youth to consider careers in health and research, particularly in the area of cancer.

**Participants:** A total of 47 students and twenty teachers and staff attended the conference. Fifteen schools in Arizona were invited to participate. These schools are primarily comprised of American Indian students.

Each school's participants were to develop a science project to be presented during the conference. Each project was judged and five prizes were awarded.

### ***Agenda***

Wednesday, December 2, 1992 agenda topics included the poster sessions, science project judging, and a key note address on Minority Health by Dr. Claudia R. Baquet.

Thursday, December 3, 1992 agenda topics included the following: Introduction to the Arizona Health Center and Arizona Cancer Center, Science and Research as a Career, Panel Discussion, "Through Cultural Lens -- Learning and Science", tour of the Arizona Cancer Center, Cancer and Research Needs for Indian Communities -- an Overview, tour of Arizona State University Campus, getting into College and Health Careers, and viewing of NARTC video, "American Indian Concepts of Wellness and Unwellness."

Friday, December 4, 1992 agenda topics included a preview of video footage shot during the conference, tour of "Science of the Future: The Biosphere 2 Model". Student survey was administered and closing comments were made prior to adjournment.

## **DIVISION OF CANCER ETIOLOGY**

The Division of Cancer Etiology (DCE) plans and directs a national program of basic research including laboratory, field epidemiologic and biometric research on the cause and natural history of cancer and means for prevention cancer. This program is implemented by intramural research, research grants, cooperative agreements, and contracts. DCE evaluated mechanisms of cancer induction and promotion by chemicals, viruses and environmental agents. This Division serves as the focal point for the federal government of the synthesis of clinical, epidemiological and experimental data relating to cancer causation. The Division also participates in the evaluation of and advises the Institute Director on program related aspects of other basic research activities as they relate to cancer cause and prevention.

### **Cancer Etiology Research targeting Native Americans (1991-1996)**

The Extramural Programs Branch, NCI, held a workshop on and issued a RFA for research on "Cancer Risks in U.S. Ethnic/Minority Populations." The Branch supports three projects at the University of New Mexico School of Medicine that address risk factors for breast and cervical cancer and leukemia and lymphoma, among New Mexico populations including American Indians.

### **Studies of HTLV in Native Americans (1988-present)**

In 1988, a high prevalence of antibodies to human T-lymphotropic viruses (HTLV-I/II) was first noted in Native Americans. HTLV-I is known to cause leukemia and neurologic disease among other disorders. HTLV-II is suspected of being pathogenic but no specific disease causation has yet been proven. Through intramurally supported programs, the National Cancer Institute has expanded its studies on HTLV in several American Indian populations, documenting that HTLV-II is the predominant HTLV infecting most groups studied to date. Attention is now being focused on which diseases, if any, are caused by this virus, and which populations are most heavily infected.

### **Intra-agency Agreement with Alaska Area Indian Health Service on Risk Factors (1992-1995)**

The Alaska Area Indian Health Service monitors temporal trends to provide cancer incidence, mortality, and survival baseline for Alaska Native populations. This new agreement targets specific malignancies for etiologic studies, with particular emphasis on diet and infections agents. Three malignancies are currently the focus of active research: lymphoma, with specific attention to Epstein-Barr virus; hepatocellular carcinoma, focusing on chemical carcinogenesis and hepatitis viruses, and cervical cancer, focusing on the possible interactions of human papilloma viruses and HTLV-II.

1. Senate Appropriations Report for Fiscal Year 1992, Report #102-104, 1991, p. 86.
2. DCBDC, NCI, *Guidelines: National Cancer Institute-Designated Comprehensive Cancer Center*, 1992 Draft, p. 4)

## CHAPTER 12: RESEARCH RECOMMENDATIONS AS SPECIFIED WITHIN A NATIONAL STRATEGIC PLAN

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### CHAPTER OBJECTIVES:

- REVIEW THE *NETWORK FOR CANCER CONTROL RESEARCH AMONG AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS'* NATIONAL STRATEGIC CANCER PLAN.
  - IDENTIFY FEDERAL AGENCY ACTION ITEMS FOR CANCER RESEARCH WHICH HAVE BEEN RECOMMENDED BY THE *NETWORK FOR CANCER CONTROL RESEARCH AMONG AMERICAN INDIAN AND ALASKA NATIVE POPULATIONS*.
  - IDENTIFY OUTCOME MEASURES FOR EACH RECOMMENDED ACTION ITEM.
- 

### INTRODUCTION

The Special Populations Studies Branch (SPSB) of the National Cancer Institute (NCI) has supported the development of a *Network for Cancer Control Research among American Indian and Alaska Native Populations* from April 1990 to the present. The mission of this research network is to improve the health of American Indian and Alaska Native peoples by reducing cancer morbidity and mortality to the lowest possible levels and to improve cancer survival through cancer control research.

Although this research network is supported by the NCI, they function as an empowered, independent organization. The Network attempts to assist the NCI in achieving the Year 2000 objectives. Each fiscal year this group of professionals identifies priority tasks which will assist in achieving its stated mission. During the latter part of 1991 and throughout 1992, the *Network for Cancer Control Research among American Indian and Alaska Native Populations* developed a National Strategic Cancer Plan. The purpose of this plan is to enhance the awareness in federal agencies, other organizations and individuals about the problems of cancer among Indigenous populations. The action items and outcome measures provide a concise summary of the types of cancer research which is needed to reduce Native American cancer incidence and mortality and to improve cancer survival among Indigenous Peoples.

The Strategic Plan is included in its entirety. The *Network for Cancer Control Research among American Indian and Alaska Native Populations* perceives this Strategic Plan to be an "active" document and plans to provide an addendum to this plan each fiscal year.

## **A National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives**



Apache Healer - Artist: Earl Sisto (Apache)

by

**The Network for Cancer Control Research among  
American Indian and Alaska Native Populations**

October 1992

**A NATIONAL STRATEGIC PLAN FOR CANCER PREVENTION AND CONTROL TO BENEFIT THE  
OVERALL HEALTH OF AMERICAN INDIANS AND ALASKA NATIVES**

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## EXECUTIVE SUMMARY

*revised May 2, 1993*

The purpose of this national strategic plan is to enhance the awareness in federal agencies, other organizations and individuals about the problems of cancer among American Indian and Alaska Native populations. Cancer is the leading cause of death for Alaska Native women, the second leading cause of death for American Indian women and the third leading cause of death in American Indian and Alaska Native men. American Indians and Alaska Natives have the poorest survival rates from all cancer sites in comparison with other racial groups such as Black Americans, Whites, and Hispanics. While cancer in American Indians and Alaska Natives was noted to be a rare disease at the beginning of this century, marked increases in cancer incidence and mortality have occurred during the last twenty years. In four of the twelve Indian Health Service (IHS) Areas, the total mortality rates already exceeds the U.S. All Races rate. Consistent with the Year 2000 objectives, this document suggests strategies to reduce cancer morbidity and mortality and to increase survival among American Indian and Alaska Native populations.

The focus of the plan is on actions and outcomes that may be of assistance to federal agencies in the development of special initiatives to address the problem of cancer among American Indians and Alaska Natives. As part of its continuing efforts to reduce cancer morbidity and mortality, the *Network for Cancer Control Research among American Indian and Alaska Native Populations* will provide annual addenda to update this plan.

A few examples of the type of Action Items which are included in this Plan follow:

- IA1. Federal agencies should improve surveillance strategies and recommend protocols that will eliminate racial and ethnic misclassification. (p. 13)
- IA2. The Secretary of Health and Human Services should take a leadership role in organizing efforts to improve communication among federal agencies such as the Bureau of Census and DHHS, which are involved with data collection. (p. 14)
- IB1. Federal agencies should provide support with policy, and the commitment of staff and financial resources to improve quality control for the collection of cancer data among American Indian and Alaska Native people. (p. 16)
- IIB2. Federal agencies should provide resources for completing and maintaining accurate documentation of cancer incidence, mortality and survival in American Indians and Alaska Natives. (p. 22)
- IIB3. An American Indian and Alaska Native professional should be hired by each federal agency as a permanent staff member to assure the commitment of that agency to programs, projects, and research in American Indian and Alaska Native populations. (p. 23)
- IIIB1. Federal agencies should sponsor research on the etiology of common cancers such as lung, colon, breast and uterine cervix to explore genetic and environmental influences that may impact the occurrence of these cancers in American Indians and Alaska Natives. (p. 26)

- IIIB2. Federal agencies should support research into the etiology in American Indian and Alaska Native people of cancers that occur at rates above national rates such as gallbladder, nasopharyngeal, stomach, and pancreas. (p. 26)
- IVA1. Federal agencies should recognize the federal government's unique relationship with American Indian and Alaska Native people and offer opportunities to nations, tribes and communities to address the cancer problem.
- IVB1. Federal agencies should sponsor an annual national conference on cancer prevention and control for American Indians and Alaska Natives. (p. 31)
- VA1. Federal agencies should evaluate the current projects that are funded for cancer research in American Indian and Alaska Native peoples. (p. 34)
- VB1. Federal agencies should insist that investigators planning cancer research programs seek active collaboration with and obtain full consent from American Indian and Alaska Native communities. (p. 35)
- VC1. Federal agencies should establish a centralized office to coordinate dissemination of successful cancer interventions among American Indian and Alaska Native people. (p. 36)

The national strategic plan was prepared by the Steering Committee of the *Network for Cancer Control Research among American Indian and Alaska Native Populations*. This Network was organized by the Special Populations Studies Branch of the Division of Cancer Prevention and Control (DCPC) of the National Cancer Institute (NCI) in April 1990.

The strategic plan for cancer prevention and control is organized into the following five "issues":

- acknowledge cancer as a major health problem in American Indian and Alaska Native populations;
- increase awareness among indigenous peoples that cancer is a growing health problem for them and that measures should be taken to prevent it;
- improve cancer survival by providing early detection, "state of the art" treatment and delivery of quality health care to this population;
- overcome the cultural and communication barriers that prevent understanding of the cancer problem; and,
- improve research in methods of evaluation of cancer prevention and control, delivery of care and techniques for overcoming barriers to optimal treatment.

Following an introduction, the first section of this plan describes these five issues and specific recommendations relating to each issue. The next section highlights background information that puts each issue into perspective. The final section contains tabular presentations describing "action items," rationale/purpose and outcome assessments that relate to specific issues and recommendations. The action items are intended to provide guidance in identifying explicit activities relevant to the objectives contained in this plan.



## A. INTRODUCTION

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During the latter part of 1991, the *Network for Cancer Control Research among American Indian and Alaska Native Populations* initiated the preparation of a national strategic plan for cancer. Contents of the plan support the objectives of the Department of Health and Human Services (DHHS) and the National Cancer Institute to reduce the cancer mortality rate in the United States by the year 2000.

The Network was developed by the Special Populations Studies Branch of the Division of Cancer Prevention and Control (DCPC) of the National Cancer Institute (NCI) in April 1990 to address the unique cancer problems of this special population who are descendants of the indigenous people of the North American continent. The Network Steering Committee comprises fifteen participants, at least 2/3 of whom are of American Indian or Alaska Native descent, who were invited to participate on the Network based on their demonstrated commitment to appropriate and quality care of American Indian and Alaska Native people. The Steering Committee includes people who are from different tribal origins and geographic locations who have expertise in medicine, epidemiology, community health, and cultural history. The National Cancer Institute in supporting the Network acknowledged the heterogeneity of American Indian and Alaska Native people and their special needs. (A description of the Network for Cancer Control Research among American Indian and Alaska Native populations and Steering Committee membership appears in Appendix A.)

The Network Steering Committee through the strategic plan hopes to educate the American public on the cultural diversity of the remnants of the many nations that once solely inhabited the North American continent. The definition of American Indian and Alaska Native is based on the tribal recognition of its own people. The racial designation of American Indian or Alaska Native as used by the U.S. Census Bureau is based on self declaration.

Federally recognized tribes receive funding for their activities from governmental agencies based on their status as sovereign nations rather than on the basis of race. Sovereignty and self-government issues are unique for American Indians and Alaska Natives and differ from the other special populations. American Indian and Alaska Native people living on reservations, in rural villages and in urban communities are recognized by their tribal affiliations. Decisions involving research and health care among American Indians and Alaska Natives require their involvement and active participation.

Cancer was considered to be rare in this population at the beginning of the Twentieth Century as reported by Hrdlicka in the Bureau of American Ethnology (1908). Documentation of the increase of cancer incidence in this special population has been demonstrated by the Indian Health Service (IHS) and by comparable studies in Canadian Indians. Data from Surveillance Epidemiology and End Results (SEER) that emphasize the poor survival rate were primarily collected in Southwestern American Indians and demonstrate a lower incidence of cancer in this population when compared to all U.S. races.

Cancer is the second leading cause of death in American Indian and Alaska Native women and the third leading cause of death in American Indian and Alaska Native men. The IHS recently published an important document on cancer mortality from 1968 through 1988 titled, Cancer Mortality among Native Americans in the United States (1992). This document provides excellent regional cancer mortality trend data. However, it identifies sources of concern in interpreting cancer statistics for American Indians and Alaska Natives. In California and

Washington state, for example, studies have shown marked underreporting of "American Indian" in the racial classification section on death certificates. It also appears that this problem exists in the Oklahoma and Portland Indian Health Service Areas (See Appendix B for IHS Area map). Therefore, throughout this publication, the mortality rates that are shown for these areas should be interpreted with caution. According to the 1990 Census, 52% of American Indians and Alaska Natives live in urban areas. The three largest urban Indian populations are located in Oklahoma City, Oklahoma, Tulsa, Oklahoma and Los Angeles, California represent. The problem of significant underreporting of cancer statistics also extends to urban Indian populations.

The strategic plan was developed by the Network Steering Committee to enhance awareness in federal agencies and in others about cancer in American Indian and Alaska Native populations and proposes activities to: (1) acknowledge cancer as a major health problem in American Indian and Alaska Native populations; (2) increase awareness among indigenous people that cancer is a growing health problem for them and that measures should be taken to prevent it; (3) improve cancer survival by providing early detection, "state of the art" treatment and delivery of quality health care to this population; (4) overcome the cultural and communication barriers that prevent understanding of the cancer problem; and, (5) improve research in methods of evaluation of cancer prevention and control, delivery of care and techniques for overcoming barriers to optimal treatment.

## **B. OVERVIEW OF ISSUES**

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This strategic plan for cancer prevention and control is organized into five issues which appear below. Recommendations for specific actions follow each issue. Further information relating to these issues appears in a separate section of the strategic plan.

### **ISSUE I. CANCER IS A MAJOR HEALTH PROBLEM FOR AMERICAN INDIANS AND ALASKA NATIVES.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the underreported mortality from cancer and other inaccurate cancer data on American Indians and Alaska Natives be recognized by federal agencies. The process of data collection should to be corrected to prevent misleading conclusions.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the overall quality of cancer data be objectively scrutinized and improved. The process of collecting American Indian and Alaska Native cancer statistics should be reviewed to reduce racial misclassification, diagnostic and/or other errors.

### **ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support public education to increase awareness of cancer as a threat to the health of American Indian and Alaska Native people through policy development, and the commitment of staff and financial resources.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

**ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies investigate the negative impact of the lack of prompt and effective treatment on the poor survival rates from cancer of American Indians and Alaska Natives.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies focus research on the etiologies of the common cancers in American Indian and Alaska Native people to reduce their high incidence and mortality rates. The disproportionate rates of gallbladder, gastric, nasopharyngeal and pancreatic cancers also suggest focused etiologic research efforts eventually aimed at reducing high incidence and mortality rates.

Recommendation C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies take steps to reduce cancer risk factors prevalent among American Indian and Alaska Native people. The need for research on the development of techniques to overcome the barriers associated with poverty, geographic isolation and cultural differences should be emphasized.

**ISSUE IV. COMMUNICATION BARRIERS EXIST AMONG AMERICAN INDIAN AND ALASKA NATIVE PEOPLE, THEIR CARE PROVIDERS AND RESEARCH SCIENTISTS.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies recognize the unique relationship that exists between the United States government and American Indian and Alaska Native nations/tribes/ communities and that this relationship affects the delivery of health care.

**Recommendation B.** The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies maintain a dialogue on health problems among American Indians and Alaska Natives and that collaborative approaches to investigate cancer incidence and to improve cancer detection, treatment and survival rates be of mutual concern to all agencies of the Department of Health and Human Services (DHHS).

**Recommendation C.** The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies acknowledge the cultural diversity of American Indian and Alaska Native people and recognize how they differ from the rest of the United States population. The failure to acknowledge these cultural differences may serve as a barrier to prevention, early detection and treatment of cancer in this population.

**ISSUE V. CANCER PREVENTION AND CONTROL INTERVENTION EFFORTS AND RESEARCH INVOLVING AMERICAN INDIANS AND ALASKA NATIVES REQUIRE A CONTINUING EVALUATION FOR PROGRAM ACCOUNTABILITY.**

**Recommendation A.** The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies through staff commitment and financial assistance improve and maintain the evaluation of cancer prevention and control efforts in American Indians and Alaska Natives.

**Recommendation B.** The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies advocate development of community partnership and program ownership. Such a policy would improve community cooperation with future cancer prevention and control efforts and provide feedback to researchers about benefits to subjects from participating in interventions. In all cases, American Indian and Alaska Native people should be fully informed about cancer prevention and control projects, encouraged to ask questions, and prior written approval and consent obtained from the appropriate tribal governmental bodies.

**Recommendation C.** The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that as information becomes available, federal agencies use and disseminate successful intervention efforts and models for replication in other American Indian and Alaska Native communities through cooperative efforts with public and private resources.

## C. THE STRATEGIC PLAN

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The Network's *National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives* recognizes the heterogeneity of indigenous peoples and acknowledges their special needs and characteristics. The Network emphasizes the importance of community identity of American Indians and Alaska Natives, and their sovereignty and self government. American Indians and Alaska Natives, through tribally determined membership and their status as sovereign nations receive health care based on these rights rather than on the basis of race. Because of these unique characteristics, all federal agencies must acknowledge the critical need for community involvement and securing the approval of the American Indians and Alaska Natives before programs are initiated.

This section of the strategic plan restates each issue and includes background information to assist in developing a clear understanding of cancer among American Indian and Alaska Native populations.

### I. Cancer is a Major Public Health Problem for American Indians and Alaska Natives.

- Cancer rates have increased significantly over the last twenty years.
- Cancer is the third leading cause of death for all ages.
- Cancer is the second leading cause of death for indigenous peoples over the age of 45.
- Cancer is the leading cause of death for Alaska Native women.
- Cancer is the second leading cause of death for American Indian women.
- Cancer is the third leading cause of death for American Indian and Alaska Native men.
- Poverty is a risk factor for cancer.
- 28% of American Indian and Alaska Native people live in poverty, which is more than twice the national average.
- 61% of American Indian and Alaska Native elders live in poverty.

Background: Cancer is the second leading cause of death in American Indian and Alaska Native women and the third leading cause of death in American Indian and Alaska Native men. The Indian Health Service (IHS) recently published an important document on cancer mortality from 1968 through 1988 titled, Cancer Mortality among Native Americans in the United States (1992).

Goal: To document the regional differences and trends over time in cancer incidence and mortality in these special populations.

**Recommendations:** The following information should be collected to improve the understanding of cancer incidence, mortality and survival in these indigenous peoples.

- A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the underreported mortality from cancer and other inaccurate cancer data on American Indians and Alaska Natives be recognized by federal agencies. The process of data collection should to be corrected to prevent misleading conclusions.
- B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the overall quality of cancer data be objectively scrutinized and improved. The process of collecting American Indian and Alaska Native cancer statistics should be reviewed to reduce racial misclassification, diagnostic and/or other errors.

**II. American Indian and Alaska Native people should be made aware that cancer is a growing health problem for them.**

- Indigenous peoples generally perceive alcohol abuse or accidents as a higher health priority than cancer.
- Cancer as a major health problem needs to be emphasized within American Indian and Alaska Native communities.
- Most indigenous languages do not include a word for "cancer."
- Available records suggest that the cancer is a recent experience (since the early 1900s) for American Indians and Alaska Natives.
- Cultural beliefs discourage open discussion of cancer within many American Indian and Alaska Native communities.

**Background:** The scientific community, health care givers and the American Indian and Alaska Native people regard cancer as a lower health priority than other issues in spite of cancer being the second leading cause of death for indigenous peoples over age 45. Carcinoma of the cervix and breast, two cancers whose survival rates can be altered by early detection in the dominant populations, are common in these women. Prostate cancer in American Indian men is common and survival could be influenced by early detection. The attitudes of some tribal communities toward cancer, health and survival among American Indians and Alaska Natives are distinctly different from that of the dominant population.

**Goal:** Awareness and understanding of cancer among American Indians and Alaska Natives can be improved through *community development strategies*. Community development strategies are initiated and controlled by indigenous people and are designed to empower the local community to implement and assess culturally appropriate programs designed to enhance understanding of cancer, the risk factors for prevention, and the need to seek treatment when cancer is first suspected.

**Recommendations:**

- A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support public education to increase awareness of cancer as a threat to the health of American Indian and Alaska Native people through policy development, and the commitment of staff and financial resources.
- B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.



**III. American Indians and Alaska Natives have among the poorest survival rates from cancer sites of all racial groups.**

- Available data indicate poor cancer survival among American Indians in the southwestern United States.
- Most accurate cancer survival data for American Indians are available for only one region of the United States.
- Few research projects have examined factors affecting cancer mortality and survival among American Indians and Alaska Natives.

**Background:** The cancer survival rates for American Indians are among the poorest of any racial group in the United States. Compared to non-Indian people in the Southwest, cancer survival for American Indians is poor, even when stage at diagnosis and treatment is considered in the survival statistics. Survival data are not yet available for American Indians or Alaska Natives in other parts of the country.

**Goal:** The poor survival rate of American Indians reported by the NCI needs to be explored in all American Indian and Alaska Native people to analyze associations of cancer with genetics, behavior, nutrition, poverty, stage of detection, treatment and/or compliance.

**Recommendations:**

- A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies investigate the negative impact of the lack of prompt and effective treatment on the poor survival rates from cancer of American Indians and Alaska Natives.
- B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies focus research on the etiologies of the common cancers in American Indian and Alaska Native people to reduce their high incidence and mortality rates. The disproportionate rates of gallbladder, gastric, nasopharyngeal and pancreatic cancers also suggest focused etiologic research efforts eventually aimed at reducing high incidence and mortality rates.
- C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies take steps to reduce cancer risk factors prevalent among American Indian and Alaska Native people. The need for research on the development of techniques to overcome the barriers associated with poverty, geographic isolation and cultural differences should be emphasized.

**IV. Communication barriers exist among American Indians and Alaska Natives and their health care providers and research scientists.**

- American Indian and Alaska Native communities need to actively participate with health care providers and research scientists in establishing and working toward Year 2000 objectives.
- There is a dearth of American Indian and Alaska Native researchers involved in cancer prevention and control programs.

**Background:** American Indian and Alaska Native people have a world view (the way of relating to the earth and participating in society), ethical values, and concerns for both the individual and community, that differ from those of many scientists and health care providers. These differing world views often contribute to misunderstanding and/or become barriers to early detection and/or treatment of cancer. For example, American Indian patients may not feel comfortable communicating their needs to the care givers, or feel that the care givers do not understand or value their concerns. Many American Indian and Alaska Native people distrust research and the researchers due to poorly conceived research in the past and the lack of feedback as to how the community benefitted from the research. Cancer is perceived to be a low priority health problem, and current methods of cancer prevention are more oriented to the individual rather than to the community. Therefore, the joint "ownership" of cancer prevention by the person and the community is difficult for both parties to understand.

**Goal:** The communication barriers which exist between American Indian and Alaska Native people and the issue of cancer prevention and control in their populations requires the unique adaptation of protocols that have been prepared by researchers aware of these special communication challenges.

**Recommendations:**

- A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies recognize the unique relationship that exists between the United States government and American Indian and Alaska Native nations/tribes/ communities and that this relationship affects the delivery of health care.
- B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies maintain a dialogue on health problems among American Indians and Alaska Natives and that collaborative approaches to investigate cancer incidence and to improve cancer detection, treatment and survival rates be of mutual concern to all agencies of the Department of Health and Human Services (DHHS).
- C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies acknowledge the cultural diversity of American Indian and Alaska Native people and recognize how they differ from the rest of the United States population. The failure to acknowledge these cultural differences may serve as a barrier to prevention, early detection and treatment of cancer in this population.

**V. Cancer prevention and control intervention efforts and research in American Indians and Alaska Natives require a continuing evaluation for program accountability.**

- Cancer prevention and control programs among American Indians and Alaska Natives require on-going evaluation to assess effectiveness.
- Successful programs need to be documented and disseminated to other communities for implementation.

**Background:** Evaluation requires quantifiable goals assessed using techniques that are acceptable to the community. It is important to recognize factors that could affect cancer prevention and control including: [1] the unique diversity of American Indian and Alaska Native people; [2] their tribal sovereignty; and [3] the rapid changes in these communities and in

cancer research. These factors require on-going evaluation of cancer prevention and control programs in these communities.

Goal: The most cost-effective, efficient, and beneficial strategies for cancer prevention and control in American Indian and Alaska Native communities must be addressed. These strategies must also be acceptable to the particular communities.

Recommendations:

- A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies through staff commitment and financial assistance improve and maintain the evaluation of cancer prevention and control efforts in American Indians and Alaska Natives.
- B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies advocate development of community partnership and program ownership. Such a policy would improve community cooperation with future cancer prevention and control efforts and provide feedback to researchers about benefits to subjects from participating in interventions. In all cases, American Indian and Alaska Native people should be fully informed about cancer prevention and control projects, encouraged to ask questions, and prior written approval and consent obtained from the appropriate tribal governmental bodies.
- C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies use and disseminate information regarding the successful intervention efforts and models for replication in other American Indian and Alaska Native communities through cooperative efforts with public and private resources.

## D. RECOMMENDED ACTIONS

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This section contains tabular presentations describing "action items" that relate to specific issues and recommendations. These action items are intended to provide guidance in identifying explicit activities relevant to the objectives contained in this plan. Brief statements highlighting the rationale/purpose and means of outcome assessment also appear for each action item.

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

## ISSUE I. CANCER IS A MAJOR HEALTH PROBLEM FOR AMERICAN INDIANS AND ALASKA NATIVES.

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the underreported mortality from cancer and other inaccurate cancer data on American Indians and Alaska Natives be recognized by federal agencies. The process of data collection should be corrected to prevent misleading conclusions.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should improve surveillance strategies and recommend protocols that will eliminate racial and ethnic misclassification.	Statistics on American Indians and Alaska Natives underestimate cancer morbidity and mortality due to racial misclassification. Most federal questionnaires and forms do not allow for the identification of "American Indian" or "Alaska Native" or tribal affiliation designations. Data regarding cancer patterns and sites among American Indians and Alaska Natives are valuable for the development of intervention strategies.	Federal agencies will contract with an unbiased independent agency to assess the magnitude of racial misclassification in all federal databases. This report will include feasible corrective recommendations, a timetable for planning and implementing recommended changes, and suggested means of evaluating their effectiveness.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES****ISSUE I. CANCER IS A MAJOR HEALTH PROBLEM FOR AMERICAN INDIANS AND ALASKA NATIVES.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the underreported mortality from cancer and other inaccurate cancer data on American Indians and Alaska Natives be recognized by federal agencies. The process of data collection should be corrected to prevent misleading conclusions.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
2. The Secretary of Health and Human Services should take a leadership role in organizing efforts to improve communication among federal agencies such as the Bureau of Census and DHHS, which are involved with data collection.	Racial misclassification affects all federal databases. Inaccurate information begins at the local level. Misinformation reported from the local level is transmitted to state and federal levels, which leads to erroneous conclusions.	Federal agencies will organize training workshops for professionals and organizations involved with collecting cancer statistics. These may be state health departments, IHS Service Units, tribal health facilities, hospital-based tumor registries, or any facilities recording health statistics information on American Indian and Alaska Native people. As a result of this collaborative effort, the federal agencies will improve data collection protocols for race and ethnic identification.

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

## ISSUE I. CANCER IS A MAJOR HEALTH PROBLEM FOR AMERICAN INDIANS AND ALASKA NATIVES.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the overall quality of cancer data be objectively scrutinized and improved. The process of collecting American Indian and Alaska Native cancer statistics should be reviewed to reduce racial misclassification, diagnostic and/or other errors.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should provide support with policy, and the commitment of staff and financial resources to improve quality control for the collection of cancer data among American Indian and Alaska Native people.	Inconsistent quality of the collection of data on cancer statistics in American Indian and Alaska Native people exists in community hospitals, IHS Service Units and tribal health facilities.	Federal agencies will develop an initiative to improve the cancer database by training tumor registrars/medical records staff who are employed by hospitals that serve American Indian and Alaska Native people. To improve the reporting of cancer staging, federal agencies will encourage hospitals that provide cancer care for American Indian and Alaska Native people to develop American College of Surgeons-approved cancer programs.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

**ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support public education to increase awareness of cancer as a threat to the health of American Indian and Alaska Native people through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should raise the awareness that cancer is a health problem by (a) developing and disseminating cancer prevention and control educational materials; (b) sending experts knowledgeable about cancer prevention and control to the public gatherings of American Indian and Alaska Native people; and (c) educating tribal leaders about cancer by including them in public forums sponsored by federal agencies.	<ul style="list-style-type: none"><li>● American Indians and Alaska Natives perceive other health issues to be of greater priority than is the problem of cancer.</li><li>● There is a lack of culturally appropriate educational materials on cancer for American Indians and Alaska Natives.</li><li>● Federal leaders need to be aware that they influence the knowledge, attitudes and behavior of American Indians and Alaska Natives regarding cancer.</li><li>● There is limited direct interaction between federal agency leaders and leaders of the American Indian and Alaska Native communities.</li></ul>	<p>Federal agencies will initiate research to develop culturally appropriate cancer education materials as well as develop appropriate protocols for dissemination to local American Indian and Alaska Native communities.</p> <p>Federal agencies will support and participate in annual national cancer meetings for American Indian and Alaska Native people.</p> <p>Federal agencies will send staff to the American Indian and Alaska Native meetings to apprise local communities of cancer research priorities.</p>



**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

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ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
	<ul style="list-style-type: none"><li>● Participation in public education by federal agencies underscores the importance of the cancer issue in American Indian and Alaska Native people.</li></ul>	<p>A knowledgeable representative from the federal government will participate by lectures, demonstrations and exhibits about cancer in this special population at meetings of American Indian and Alaska Native people such as:</p> <ul style="list-style-type: none"><li>● National Congress of American Indians</li><li>● National Indian Health Board</li><li>● Inter-Tribal Meetings</li><li>● Wellness and Women Annual Conference</li><li>● Wellness and Men Annual Conference</li></ul>

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support public education to increase awareness of cancer as a threat to the health of American Indian and Alaska Native people through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
2. Federal agencies should provide staff support and financial assistance to disseminate the National Strategic Cancer Plan to American Indian and Alaska Native people in a form that can be utilized by local communities.	To make certain that there is proper and accurate communication of the plan throughout all American Indian and Alaska Native groups.	<p>The National Strategic Cancer Plan will be disseminated to the following groups:</p> <ul style="list-style-type: none"><li>● Federally recognized tribes (currently 512)</li><li>● urban American Indian health clinics (currently 34)</li><li>● American Indian owned and operated health facilities</li><li>● Alaska Native Health corporations</li><li>● American Indian and Alaska Native community organizations</li><li>● Other research and training centers</li><li>● Voluntary agencies</li><li>● Federal agencies</li></ul>

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support public education to increase awareness of cancer as a threat to the health of American Indian and Alaska Native people through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
3. Federal agencies should take steps to encourage the development of leadership capacity and consortium development within American Indian and Alaska Native communities.	Local leadership is needed to increase skills and empowerment to address cancer concerns within local indigenous communities.	Federal agencies will initiate the development of a national network for American Indians and Alaska Natives, both lay and professional, to address local cancer priorities.

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should raise the awareness that cancer is a health problem in American Indian and Alaska Native professionals.	<p>Many professionals are not aware that cancer is a major health problem for American Indians and Alaska Natives. There are few researchers involved in American Indian and Alaska Native cancer research. Federal leaders influence the direction of clinical investigation and research on the cancer problems in these special populations. Participation in professional education by federal agencies influences cancer research and underscores the importance of the cancer issue to this special population.</p>	<ul style="list-style-type: none"><li>● Federal agencies will initiate research to evaluate and assess culturally appropriate cancer education materials and the effectiveness of protocols for dissemination.</li><li>● Federal agencies will support and participate in an annual national scientific meeting on cancer in this special population.</li><li>● Federal agencies will send staff to professional meetings to participate and provide updates of American Indian and Alaska Native cancer research priorities.</li></ul>

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

**ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.**

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
		<ul style="list-style-type: none"><li>● A representative from the federal government and the <i>Network for Cancer Control Research among American Indian and Alaska Native Populations</i> will participate by lectures, demonstrations</li></ul>

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
		and exhibits in scientific meetings related to cancer such as the following: <ul style="list-style-type: none"><li>• American Society for Clinical Oncology</li><li>• American Public Health Association</li><li>• American Association for Cancer Education</li><li>• American Association for Cancer Research</li><li>• American Society for Preventive Oncology</li><li>• Meetings of clinical cooperative groups</li><li>• American Medical Association</li><li>• National Medical Association</li><li>• Association for American Indian Physicians</li><li>• American College of Physicians</li><li>• Indian Health Service Health Providers and Clinicians Meeting</li><li>• American College of Surgeons</li></ul>

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

## ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

ACTION	RATIONALE/PURPOSE	OUTCOME
2. Federal agencies should provide resources for completing and maintaining accurate documentation of cancer incidence, mortality and survival in American Indians and Alaska Natives.	<p>Information about cancer incidence, mortality and survival in American Indians and Alaska Natives is fragmented.</p> <p>A comprehensive bibliography on cancer in American Indians and Alaska Natives would assist researchers, community health planners and others in planning cancer programs.</p>	<p>An annotated bibliography of literature and a summary of on-going funded research projects and innovative American Indian and Alaska Native cancer programs will be made available for dissemination.</p>

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE II. AMERICAN INDIAN AND ALASKA NATIVE PEOPLE SHOULD BE MADE AWARE THAT CANCER IS A GROWING HEALTH PROBLEM FOR THEM.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies support professional education of scientists, health professionals and care givers to enhance their awareness of cancer in these indigenous populations through policy development, and the commitment of staff and financial resources.

ACTION	RATIONALE/PURPOSE	OUTCOME
3. An American Indian and Alaska Native professional should be hired by each federal agency as a permanent staff member to assure the commitment of that agency to programs, projects, and research in American Indian and Alaska Native populations.	There are too few American Indian and Alaska Native people in professional staff positions in federal health agencies involved with cancer research. The visibility of indigenous professional staff would serve as a reminder that the health needs of American Indian and Alaska Native people need to be recognized. Indigenous professional staff who have retained their cultural identity would provide assistance to federal agencies in maintaining high levels of cultural competence and effectiveness in the research process.	Federal Agencies will recruit American Indian and Alaska Native professional staff to coordinate research projects on American Indians and Alaska Natives.



## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that the federal agencies investigate the negative impact of the lack of prompt and effective treatment on the poor survival rates from cancer among American Indians and Alaska Natives.

ACTION	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should organize efforts to develop study data collection to document survival from cancer in American Indian and Alaska Native people.	Available information suggests that American Indians and Alaska Natives have lower survival rates from cancer even when adjusted for stage at diagnosis and treatment.	Federal agencies will develop a standardized approach to collecting data on survival from cancer.
2. Federal agencies should investigate the negative impact of the lack of prompt and effective cancer treatment as a cause of the poor survival rates.	Research in other populations has established the link between prompt and effective treatment and improved cancer survival.	Federal agencies will support programs for early detection and assure state-of-the-art treatment to American Indian and Alaska Native people with cancer. The registration of American Indian and Alaska Native people in NCI-approved cancer treatment protocols will be encouraged by the cooperative groups.

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

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ACTION	RATIONALE/PURPOSE	OUTCOME
3. Federal agencies should sponsor cancer research to investigate the poor survival rates from cancer of American Indian and Alaska Native people.	Survival data are available only for American Indians of the Southwest as reported by the SEER data.	Federal agencies will provide financial assistance to support the SEER-like data with comparable databases in regions with American Indian and Alaska Native populations.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies focus research on the etiologies of the common cancers in American Indian and Alaska Native people to reduce their high incidence and mortality rates. The disproportionate rates of gallbladder, gastric, nasopharyngeal and pancreatic cancers also suggest focused etiologic research efforts eventually aimed at reducing high incidence and mortality rates.

ACTION	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should sponsor research on the etiology of common cancers such as lung, colon, breast and uterine cervix to explore genetic and environmental influences.	Lung cancer rates vary by IHS area and correlate with smoking prevalence in the observed populations. There is a lack of information on the etiologic factors related to breast, uterine cervix and colon cancers among American Indian and Alaska Native people.	Federal agencies will support research on etiologic factors related to common cancers in American Indian and Alaska Native populations.
2. Federal agencies should support research into the etiology in American Indian and Alaska Native people of disproportionate cancers such as gallbladder, nasopharyngeal, stomach, and pancreas.	Elevated mortality rates for cancer of these sites have been reported among American Indian and Alaska Native populations. There is a lack of information on the etiologic factors related to these cancers.	Federal agencies will support research on the etiologic factors related to carcinoma of the gallbladder, pancreas and stomach and explore the genetic etiology suggested by some researchers.

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.

Recommendation C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies take steps to reduce cancer risk factors prevalent among American Indian and Alaska Native people. The need for research on the development of techniques to overcome the barriers associated with poverty, geographic isolation and cultural differences should be emphasized.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should sponsor Phase I and II cancer research among American Indians and Alaska Natives. Phase I projects include the development of hypotheses, identification of risk factors, development of knowledge, attitude and behavior survey instruments, and the collection of baseline data. Phase II projects include the development of methodology which can be used later for interventions.	Phase I baseline information is available for only a few of the American Indian and Alaska Native communities. Specific differences exist among American Indian and Alaska Native communities as well as between them and all races in the U.S. population. The differences include the geographic isolation of many Indian and Native Reservations. Cultural barriers exist for both rural and urban areas.	The federal agencies will release every three years requests for applications for Phase I and II cancer research projects among American Indians and Alaska Natives.

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.

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ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
2. Federal agencies should continue to sponsor Phase III cancer research projects to test the efficacy issues of cancer interventions among American Indians and Alaska Natives.	Valuable data have been accumulated by the currently active National Cancer Institute cooperative agreements for both the "Avoidable Mortality and the Primary Prevention Cancer Research interventions among Native Americans." However, the data are limited to eleven American Indian and Alaska Native sites.	To address the heterogeneity of the American Indian and Alaska Native populations, the NCI will issue Phase III Requests for applications (RFA) for intervention research among indigenous communities.

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE III. AMERICAN INDIANS AND ALASKA NATIVES HAVE AMONG THE POOREST SURVIVAL RATES FROM CANCER OF ALL RACIAL GROUPS. SPECIFIC CANCERS NOT COMMONLY OBSERVED IN THE GENERAL POPULATION OCCUR AT HIGH RATES IN THE AMERICAN INDIAN AND ALASKA NATIVE PEOPLE AND WARRANT SPECIAL ATTENTION.

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ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
3. Federal agencies should sponsor and encourage the development of Phase IV and V (community trials and demonstration projects) cancer intervention trials for American Indians and Alaska Natives.	Successful federally funded demonstration projects and community trials provide evidence to convince the communities to invest their local resources in continuing these programs.	The NCI will develop and issue Phase IV and V RFAs for cancer prevention and control programs for American Indian and Alaska Native people.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

**ISSUE IV. COMMUNICATION BARRIERS EXIST AMONG AMERICAN INDIAN AND ALASKA NATIVE PEOPLE, THEIR CARE PROVIDERS AND RESEARCH SCIENTISTS.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies recognize the unique relationship that exists between the United States government and American Indian and Alaska Native nations/tribes/communities and that this relationship affects the delivery of health care.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should recognize the federal government's unique relationship with American Indian and Alaska Native people and offer opportunities to nations, tribes and communities to address the cancer problem.	The unique relationship of American Indian and Alaska Native people to the federal government is based upon their inherent sovereignty as independent nations, Acts of Congress, treaties, judicial decisions, and other legal agreements.	All federal agencies will recognize the unique status of these special populations by recruiting American Indian and Alaska Native professionals who are aware of this special relationship to participate on cancer advisory boards, cancer research review committees and decision-making bodies who are concerned with cancer.

## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

### ISSUE IV. COMMUNICATION BARRIERS EXIST AMONG AMERICAN INDIAN AND ALASKA NATIVE PEOPLE, THEIR CARE PROVIDERS AND RESEARCH SCIENTISTS.

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies maintain a dialogue on health problems among American Indians and Alaska Natives and that collaborative approaches to investigate cancer incidence and to improve cancer detection, treatment and survival rates be of mutual concern to all agencies of the DHHS.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should sponsor an annual national conference on cancer prevention and control for American Indians and Alaska Natives.	The annual forum would permit tribal communities and researchers to collaborate on planning innovative cancer research projects as well as provide the American Indians and Alaska Natives with an update on state-of-the-art cancer prevention and control. Workshops on preparation of grant applications could be held at the same time. This would be an opportunity to disseminate cancer education materials. In addition, this would be an opportunity for the annual recruitment of American Indian and Alaska Native people into special training and fellowship programs sponsored by DHHS.	Federal agencies will sponsor an annual national research conference on cancer prevention and control for American Indians and Alaska Natives.



## ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

## ISSUE IV. COMMUNICATION BARRIERS EXIST AMONG AMERICAN INDIAN AND ALASKA NATIVE PEOPLE, THEIR CARE PROVIDERS AND RESEARCH SCIENTISTS.

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ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
2. Federal agencies should provide training in applying for federal grants and contracts to selected American Indian and Alaska Native professionals.	Few American Indian and Alaska Native scientists serve as principal investigators on federally-funded cancer research projects.	Federal agencies will develop strategies (e.g., workshops, research assistantships, post-doctoral training, subcontracts) to recruit American Indian and Alaska Native professionals for training in the preparation of competitive research proposals.
3. Federal agencies should collaborate on cancer-related projects for American Indian and Alaska Native people.	The organization of federal agencies results in fragmentation of efforts to conceive, implement, and evaluate cancer programs.	Federal agencies will collaborate in the implementation of legislation having to do with specific cancers in American Indian and Alaska Native people. Recruitment of American Indian and Alaska Native people into positions responsible for the implementation of the legislation should be undertaken.

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE IV. COMMUNICATION BARRIERS EXIST AMONG AMERICAN INDIAN AND ALASKA NATIVE PEOPLE, THEIR CARE PROVIDERS AND RESEARCH SCIENTISTS.

Recommendation C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies acknowledge the cultural diversity of American Indian and Alaska Native people and recognize how they differ from the rest of the United States population. The failure to acknowledge these cultural differences may serve as a barrier to prevention, early detection and treatment of cancer in these populations.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should recognize the cultural diversity of American Indian and Alaska Native people and support efforts to ensure that professionals (e.g. health care providers and researchers) working with these populations recognize these special differences.	American Indian and Alaska Native people exist in rare harmony with their environment and appreciate the interdependence of all living creatures. This attitude differs from the concerns, values and objectives of many Western scientists and health care providers. Because of these distinct cultural values, the reactions of American Indian and Alaska Native people to cancer screening, diagnosis and treatment is different and may result in their delay in seeking or accepting cancer treatment. American Indian and Alaska Native people infrequently use cancer programs.	Federal agencies will support research to develop culturally appropriate and relevant approaches to address cancer screening, diagnosis and treatment in American Indian and Alaska Native communities.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES**

**ISSUE V. CANCER PREVENTION AND CONTROL INTERVENTION EFFORTS AND RESEARCH IN AMERICAN INDIANS AND ALASKA NATIVES REQUIRE A CONTINUING EVALUATION FOR PROGRAM ACCOUNTABILITY.**

Recommendation A. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies improve the evaluation of cancer prevention and control efforts in American Indians and Alaska Natives.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should evaluate the current projects that are funded for cancer research in American Indian and Alaska Native peoples.	Evaluations must include inquiry into the appropriateness of instruments designed for populations other than American Indians and Alaska Natives. Such evaluations will provide information on effectiveness and accountability of programs and provide a framework for American Indian and Alaska Native communities to develop future research and incorporate the results into community action.	Federal agencies will require thorough evaluation of research projects involving American Indian and Alaska Native peoples.

**ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES****ISSUE V. CANCER PREVENTION AND CONTROL INTERVENTION EFFORTS AND RESEARCH IN AMERICAN INDIANS AND ALASKA NATIVES REQUIRE A CONTINUING EVALUATION FOR PROGRAM ACCOUNTABILITY.**

Recommendation B. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies advocate development of community partnership and program ownership. Such a policy would improve community cooperation with future cancer prevention and control efforts and provide feedback to researchers about benefits to subjects from participating in interventions. In all cases, American Indian and Alaska Native people should be fully informed about cancer prevention and control projects, encouraged to ask questions, and prior written approval and consent obtained from the appropriate tribal governmental bodies.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should insist that investigators planning cancer research programs seek active collaboration with and obtain full consent from American Indian and Alaska Native communities.	Community-based cancer research will only be successful with the cooperation and involvement of the target population.	A joint ownership of cancer prevention and early detection research programs will be developed and implemented to assure the participation of American Indian and Alaska Native people.

ACTION ITEMS, RATIONALE/PURPOSE AND OUTCOMES FOR FEDERAL AGENCIES

ISSUE V. CANCER PREVENTION AND CONTROL INTERVENTION EFFORTS AND RESEARCH IN AMERICAN INDIANS AND ALASKA NATIVE REQUIRE A CONTINUING EVALUATION FOR PROGRAM ACCOUNTABILITY.

Recommendation C. The Network for Cancer Control Research among American Indian and Alaska Native Populations recommends that federal agencies use and disseminate information regarding the successful intervention efforts and models for replication in other American Indian and Alaska Native communities through cooperative efforts with public and private resources.

ACTION ITEM	RATIONALE/PURPOSE	OUTCOME
1. Federal agencies should establish a centralized office to coordinate dissemination of successful cancer interventions among American Indian and Alaska Native people.	Effective communication is a basic element in scientific and cultural development. American Indian and Alaska Native local populations have frequently been involved in research projects without ever receiving or being apprised of the findings.	<p>Federal agencies will publish a directory of on-going research programs, methods, strategies and evaluation results describing cancer research programs among American Indian and Alaska Native people.</p> <p>This directory will be updated every four years and will be disseminated to the following:</p> <ul style="list-style-type: none"><li>• Federally recognized tribes (currently 512)</li><li>• urban American Indian health clinics (currently 34)</li><li>• American Indian owned and operated health facilities</li><li>• Alaska Native Health corporations</li><li>• American Indian and Alaska Native community organizations</li><li>• Other research and training centers</li><li>• Voluntary agencies</li><li>• Federal agencies</li></ul>

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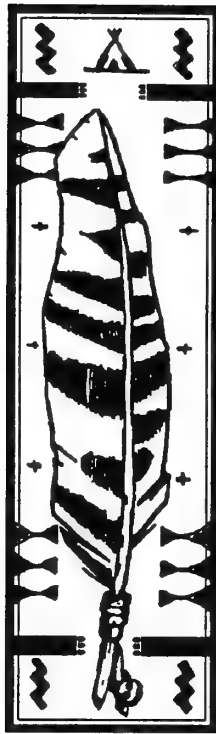
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# APPENDICES



# APPENDIX A. TABLE A.1 URBAN INDIAN HEALTH PROGRAMS AND CANCER DEATHS

Number of cancer deaths from 1983-85, Number of urban Indian service population for 34 Urban American Indian Clinics

ST	Urban Indian Health Programs	Cancer Deaths/Urban Indian Service Population (%)
AZ	Indian Community Health Services, Phoenix <sup>1</sup>	24/388 (6.2%)
AZ	Traditional Indian Alliance, Tucson <sup>1</sup>	27/371 (7.3%)
CA	American Indian Clinic, Inc., Bellflower <sup>1</sup>	52/338 (15.4%)
CA	American Indian Council, Bakersfield <sup>2</sup>	5/17 (29.4%)
CA	Central Valley Indian Health, Clovis <sup>1</sup>	5/43 (11.6%)
CA	Sacramento Urban Indian Health Project <sup>1</sup>	10/79 (12.7%)
CA	Indian Health Center of Santa Clara Valley, San Jose <sup>1</sup>	16/82 (19.5%)
CA	San Francisco Urban Indian Health Board <sup>1</sup>	30/166 (18.1%)
CA	San Diego Indian Health Program <sup>1</sup>	15/123 (12.2%)
CA	Santa Barbara Urban Indian Health <sup>2</sup>	3/7 (43.0%)
CO	Denver Indian Health Board <sup>3</sup>	8/80 (10%)
IL	American Indian Health Services, Chicago <sup>1</sup>	19/113 (16.8%)
KS	Wichita Urban Indian Health Center, Inc. <sup>1</sup>	8/19 (42.1%)
MA	Boston Indian Council <sup>3</sup>	6/25 (24%)
MI	Detroit American Indian Health Center <sup>1</sup>	12/84 (14.3%)
MN	Indian Health Board of Minneapolis <sup>1</sup>	38/198 (19.2%)
MT	Helena Indian Alliance <sup>1</sup>	4/9 (44.4%)



ST	Urban Indian Health Programs	Cancer Deaths/Urban Indian Service Population (%)
MT	Indian Health Board of Billings <sup>1</sup>	4/22 (18.2%)
MT	Native American Center, Inc., Great Falls <sup>1</sup>	1/36 (2.8%)
MT	Native American Services Agency, Missoula <sup>1</sup>	1/16 (6.3%)
MT	North American Indian Alliance, Butte <sup>1</sup>	0/4 (0.0%)
NV	Nevada Urban Indians, Inc., Reno <sup>1</sup>	7/74 (9.5%)
NM	Albuquerque Urban Indian Health Clinic <sup>1</sup>	42/337 (12.5%)
NY	American Indian Community House, NYC <sup>3</sup>	12/61 (19.7%)
OK	Indian Health Care Resource Center, Tulsa <sup>1,4</sup>	[no data]
OK	Oklahoma City Indian Clinic, Oklahoma City <sup>1,4</sup>	[no data]
OR	Portland Indian Health Service <sup>1</sup>	3/89 (3.4%)
SD	South Dakota Urban Indian Health, Pierre <sup>1</sup>	0/13 (0.0%)
TX	Dallas Inter Tribal Center <sup>1</sup>	6/51 (11.8%)
UT	Indian Health Care Clinic, Salt Lake <sup>1</sup>	2/63 (3.2%)
WA	Seattle Indian Health Board <sup>1</sup>	31/245 (12.7%)
WA	Spokane Urban Indian Health Services <sup>1</sup>	10/61 (16.4%)
WI	Milwaukee Indian Health Board <sup>1</sup>	9/73 (12.3%)
WI	United Amerindian Health Center, Green Bay <sup>3</sup>	6/40 (15%)

Footnotes

<sup>1</sup> Provides medical services

<sup>2</sup> Provides dental but no medical services

<sup>3</sup> Provides no medical or dental services; outreach and informational services only

<sup>4</sup> IHS Demonstration Project

APPENDIX B. TABLE B.1 CANCER INCIDENCE RATES BY RACE AND CANCER SITE

Age-adjusted (1970 Standard) Cancer Incidence Rates per 100,000 Population by Race and Cancer Site, Both Sexes, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	359.2	381.9	265.6	259.4	226.1	157.3	244.9	367.1	314.3
Oral cavity & pharynx	11.7	14.9	15.8	5.0	9.1	2.1	6.5	9.2	15.5
Esophagus	3.4	11.5	3.5	3.0	3.7	1.1	1.6	7.8	6.1
Stomach	8.9	14.5	11.0	28.7	8.4	17.6	15.2	28.8	15.5
Colon & rectum	52.8	50.2	42.2	51.2	31.7	10.2	26.4	32.7	62.6
Liver	2.0	3.4	11.9	4.8	6.5	2.5	3.0	5.7	6.4
Gallbladder	1.3	1.0	1.0	1.6	1.4	10.9	4.6	1.3	10.6
Pancreas	9.5	13.8	8.6	8.9	6.3	5.8	10.9	11.0	9.9
Lung & bronchus	56.2	69.4	44.2	30.1	30.0	7.3	23.3	73.6	46.9
Melanoma (skin)	9.6	0.8	0.8	1.3	1.0	2.1	1.9	1.1	N/A
Breast*	93.3	74.9	59.5	56.6	42.5	21.7	52.6	108.5	44.2
Cervix uteri*	8.6	19.5	10.5	6.0	9.2	20.5	16.1	15.2	28.0
Corpus & Uterus NOS*	26.5	15.0	18.1	18.0	11.5	7.6	12.0	29.4	N/A
Ovary*	14.1	10.1	9.5	9.1	9.8	7.8	11.2	15.1	9.5
Prostate gland#	73.6	126.0	31.4	46.3	46.4	37.6	75.8	58.2	34.5
Urinary bladder	18.1	9.6	9.2	8.2	4.6	1.6	7.9	8.8	6.1
Kidney & renal pelvis	7.2	6.8	3.7	4.1	3.4	7.5	6.4	4.6	11.2
Brain & CNS	6.3	3.4	2.9	2.8	2.3	1.6	3.7	3.3	2.1
Hodgkin's disease	3.2	1.8	0.6	0.5	1.4	0.3	2.5	1.0	N/A
Non-Hodgkin's lymphoma	11.1	7.2	8.7	7.4	8.5	2.9	6.7	8.6	N/A
Multiple Myeloma	3.7	8.6	2.0	1.4	3.5	3.7	2.7	6.3	N/A
Leukemia	10.7	9.3	5.0	6.1	7.3	5.1	6.9	8.4	N/A

DATA SOURCE: Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut NOTE: " " figures indicate the highest incidence rate of any racial group  
Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii  
Native Hawaiian - Hawaii  
American Indian - New Mexico, Arizona  
Hispanic - New Mexico  
Alaska Native - State of Alaska, 1969-83 (based on data from Lanier and Knutson, 1986)  
\*\* indicates female data only  
# indicates male data only

Age-adjusted (1970 Standard) Cancer Incidence Rates per 100,000 Population by Race and Cancer Site, Females Only, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	326.2	297.8	239.5	220.1	189.7	158.4	219.3	351.8	300.6
Oral cavity & pharynx	7.1	7.6	9.1	2.6	7.2	1.3	2.8	8.6	15.7
Esophagus	1.9	5.2	1.0	0.6	1.8	0.4	0.8	1.9	3.4
Stomach	5.8	8.6	8.5	19.0	5.7	13.8	10.2	19.5	8.4
Colon & rectum	44.9	45.9	33.8	39.6	19.4	10.0	24.0	23.3	65.2
Liver	1.2	1.9	3.9	2.0	3.5	1.1	1.7	2.7	2.0
Gallbladder	1.6	1.2	0.8	1.6	1.2	1.7	7.6	1.0	14.7
Pancreas	7.9	11.4	8.3	7.3	4.1	4.5	10.4	10.4	9.6
Lung & bronchus	33.3	30.8	26.8	13.8	17.9	4.4	14.4	45.8	23.2
Melanoma (skin)	8.8	0.8	1.0	1.0	0.6	1.6	2.5	0.8	N/A
Breast	93.3	74.9	59.5	56.6	42.5	21.7	52.6	108.5	44.2
Cervix uteri	8.6	19.5	10.5	6.0	9.2	20.5	16.1	15.2	28.0
Corpus & Uterus NOS	26.5	15.0	18.1	18.0	11.5	7.6	12.0	29.4	N/A
Ovary	14.1	10.1	9.5	9.1	9.8	7.8	11.2	15.1	9.5
Urinary bladder	8.3	5.5	3.9	4.7	3.2	0.4	3.8	5.7	3.4
Kidney & renal pelvis	4.5	4.5	2.7	2.2	2.0	7.3	4.0	2.5	11.0
Brain & CNS	5.3	2.8	2.6	2.4	0.9	1.1	2.1	3.5	1.5
Hodgkin's disease	2.7	1.3	0.7	0.3	1.3	0.5	1.1	0.6	N/A
Non-Hodgkin's lymphoma	9.6	6.0	6.9	6.4	7.0	3.2	5.7	6.8	N/A
Multiple Myeloma	3.2	7.4	1.7	1.4	2.4	3.7	2.8	6.6	N/A
Leukemia	8.2	7.5	3.6	4.9	5.9	4.6	6.1	6.7	N/A
DATA SOURCE: Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut    NOTE: " " figures indicate the highest incidence rate of any racial group Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii Native Hawaiian - Hawaii American Indian - New Mexico, Arizona Hispanic - New Mexico Alaska Native - State of Alaska, 1969-83 (based on data from Lanier and Knutson, 1986)									

Age-adjusted (1970 Standard) Cancer Incidence Rates per 100,000 Population by Race and Cancer Site, Males Only, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	421.5	502.4	298.8	312.0	237.1	155.4	276.4	392.2	329.7
Oral cavity & pharynx	17.6	24.0	23.1	8.0	10.7	3.0	10.8	9.9	17.2
Esophagus	5.5	19.6	6.4	5.9	4.9	1.8	2.6	14.7	8.9
Stomach	13.3	22.5	13.8	41.3	9.9	22.3	21.0	40.5	22.4
Colon & rectum	64.5	56.4	52.2	65.1	38.5	10.6	29.2	43.2	61.0
Liver	3.1	5.3	20.8	8.1	9.1	4.1	4.5	8.8	10.8
Gallbladder	0.9	0.8	1.3	1.7	1.4	6.4	1.2	1.5	6.7
Pancreas	11.6	17.0	8.7	10.7	8.0	7.1	11.5	11.4	10.1
Lung & bronchus	88.6	120.4	63.3	50.6	39.1	10.5	33.6	103.7	69.7
Melanoma (skin)	10.7	0.9	0.6	1.6	1.1	2.7	1.3	1.4	N/A
Breast	0.9	1.2	0.7	0.4	0.4	N/A	0.3	0.8	0.4
Prostate gland	73.6	126.0	31.4	46.3	46.4	37.6	75.8	58.2	34.5
Urinary bladder	32.0	15.4	15.1	12.3	5.5	2.8	12.6	12.8	8.9
Kidney & renal pelvis	10.7	9.7	4.9	6.5	4.6	8.1	9.1	6.9	11.4
Brain & CNS	7.5	4.3	3.4	3.2	3.5	2.1	5.4	3.1	2.8
Hodgkin's disease	3.8	2.5	0.6	0.8	1.5	0.2	4.1	1.6	N/A
Non-Hodgkin's lymphoma	13.0	8.7	10.8	8.8	9.6	2.6	7.8	10.4	N/A
Multiple Myeloma	4.5	10.3	2.4	1.4	4.1	3.6	2.5	6.6	N/A
Leukemia	14.2	11.8	6.5	7.7	8.4	5.6	7.8	9.9	N/A
DATA SOURCE: Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut    NOTE: " " figures indicate the highest incidence rate of any racial group Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii Native Hawaiian - Hawaii American Indian - New Mexico, Arizona Hispanic - New Mexico Alaska Native - State of Alaska, 1969-83 (based on data from Lanier and Knutson, 1986)									

# APPENDIX C. TABLE C.1 CANCER MORTALITY RATES BY RATES AND CANCER SITE

Age-adjusted (1970 Standard) Cancer Mortality Rates per 100,000 Population by Race and Cancer Site, Both Sexes Only, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	163.8	210.0	125.8	106.7	72.8	89.4	132.0	208.0	192.9
Oral cavity & pharynx	3.3	5.7	5.4	1.7	2.4	1.8	1.9	3.9	8.3
Esophagus	2.6	9.1	2.8	2.1	1.9	2.0	1.7	7.3	3.1
Stomach	5.2	10.0	7.7	17.7	3.6	5.8	11.8	21.8	11.9
Colon & rectum	21.3	22.4	18.1	16.6	8.0	9.0	13.2	14.8	24.6
Liver	1.9	3.6	10.2	3.3	3.6	2.0	3.8	5.3	9.0
Gallbladder	0.9	0.7	0.7	1.0	0.6	2.6	3.2	0.5	3.8
Pancreas	8.3	11.2	6.5	6.9	3.6	4.6	10.2	10.1	9.7
Lung & bronchus	41.5	51.4	31.9	19.6	14.6	18.1	19.5	56.7	40.1
Melanoma (skin)	2.2	0.4	0.3	0.2	0.3	0.3	0.4	0.3	N/A
Breast*	26.7	26.9	12.1	10.1	8.0	9.0	19.4	37.8	12.8
Cervix uteri*	3.2	8.7	3.4	2.1	1.9	5.5	4.2	5.6	12.5
Corpus & Uterus NOS*	3.8	6.5	2.7	2.3	1.8	1.8	2.3	6.6	1.1
Ovary*	8.1	6.4	3.9	4.4	2.7	3.2	5.9	8.4	5.2
Prostate gland#	21.1	44.0	7.5	8.4	8.7	11.8	19.4	15.6	11.4
Urinary bladder	3.8	3.8	1.7	1.8	1.4	1.0	2.3	2.9	1.9
Kidney & renal pelvis	3.2	2.7	1.7	1.6	0.9	2.7	2.6	2.4	5.5
Brain & CNS	4.1	2.4	1.3	1.2	1.1	1.3	3.2	2.0	2.1
Hodgkin's disease	0.9	0.7	0.3	0.1	0.3	0.3	1.0	0.2	N/A
Non-Hodgkin's lymphoma	5.2	3.3	2.9	3.5	3.4	2.1	3.1	5.6	3.7
Multiple Myeloma	2.4	5.1	1.4	1.3	1.5	1.8	2.0	3.7	2.7
Leukemia	6.7	5.8	4.2	3.5	4.1	2.9	4.8	6.8	3.5

**DATA SOURCE:** Blacks, Whites, Chinese, Japanese, Filipino, American Indians - United States (NCHS mortality data)  
Native Hawaiian - Hawaii  
Hispanic - New Mexico, 1977-82  
Alaska Native - Alaska, 1977-83

**NOTE:** " " figures indicate the highest mortality rate for any racial group  
"\*\*\*" indicates female data only  
"#\*" indicates male data only

Age-adjusted (1970 Standard) Cancer Mortality Rates per 100,000 Population by Race and Cancer Site, Females Only, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	133.2	154.0	94.2	83.2	49.0	76.2	116.5	178.6	162.8
Oral cavity & pharynx	1.8	2.4	2.7	0.8	1.3	1.3	1.3	2.2	6.3
Esophagus	1.2	3.9	0.9	0.8	0.3	0.8	0.5	2.0	1.7
Stomach	3.6	6.5	5.3	12.9	2.6	4.3	8.7	14.6	7.0
Colon & rectum	18.4	20.3	12.6	12.7	4.2	8.0	11.3	12.7	27.2
Liver	1.3	2.1	3.8	2.0	1.3	1.1	2.7	3.0	2.6
Gallbladder	1.2	0.9	0.9	1.2	0.6	3.6	4.6	0.3	6.3
Pancreas	6.8	9.3	5.3	5.9	2.1	4.2	9.1	9.5	10.3
Lung & bronchus	20.9	20.8	18.7	8.6	7.0	9.3	12.0	35.3	15.0
Melanoma (skin)	1.6	0.4	0.2	0.1	0.3	0.1	0.5	0.3	N/A
Breast	26.7	26.9	12.1	10.1	8.0	9.0	19.4	37.8	12.8
Cervix uteri	3.2	8.7	3.4	2.1	1.9	5.5	4.2	5.6	12.6
Corpus & Uterus NOS	3.8	6.5	2.7	2.3	1.8	1.8	2.3	6.6	2.1
Ovary	8.1	6.4	3.9	4.4	2.7	3.2	5.9	8.4	5.2
Urinary bladder	1.9	2.6	1.0	1.4	0.7	0.5	1.2	2.5	1.1
Kidney & renal pelvis	2.1	1.8	1.1	1.0	0.5	2.0	1.7	0.2	1.1
Brain & CNS	3.4	1.9	1.1	1.1	0.7	1.1	2.0	2.0	1.9
Hodgkin's disease	0.7	0.5	0.1	0.0	0.2	0.1	0.7	0.3	N/A
Non-Hodgkin's lymphoma	4.4	2.6	2.6	2.9	2.6	1.8	2.8	3.7	3.1
Multiple Myeloma	2.0	4.2	1.0	1.0	0.7	1.6	1.6	3.5	1.5
Leukemia	5.2	4.7	3.1	2.4	2.4	2.2	4.2	5.3	2.5

**DATA SOURCE:** Blacks, Whites, Chinese, Japanese, Filipino, American Indians - United States (NCHS mortality data)  
 Native Hawaiian - Hawaii  
 Hispanic - New Mexico, 1977-82  
 Alaska Native - Alaska, 1977-83

**NOTE:** " " figures indicate the highest mortality rate for any racial group

Age-adjusted (1970 Standard) Cancer Mortality Rates per 100,000 Population by Race and Cancer Site, Males Only, 1977-83									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	209.6	289.1	158.9	138.3	84.5	106.3	150.1	243.7	223.9
Oral cavity & pharynx	5.1	9.9	8.1	2.8	3.1	2.3	2.6	5.9	10.2
Esophagus	4.5	16.0	4.8	3.9	2.6	3.4	3.0	13.5	4.4
Stomach	7.6	14.9	10.2	24.3	4.0	7.6	15.4	32.1	17.2
Colon & rectum	25.6	25.4	23.9	21.8	9.9	10.1	15.4	17.5	22.1
Liver	2.7	5.6	16.6	4.9	5.4	3.1	5.1	7.5	15.2
Gallbladder	0.6	0.5	0.5	0.9	0.7	1.5	1.5	0.7	1.4
Pancreas	10.4	13.9	7.6	8.3	4.6	5.3	11.6	10.6	9.3
Lung & bronchus	69.5	92.6	45.4	33.9	20.1	28.8	28.2	79.9	64.9
Melanoma (skin)	2.8	0.5	0.4	0.3	0.3	0.5	0.2	0.2	0.6
Breast	0.2	0.4	0.2	N/A	0.2	0.0	0.1	N/A	N/A
Prostate gland	21.1	44.0	7.5	8.4	8.7	11.8	19.4	15.6	11.4
Urinary bladder	6.8	5.4	2.6	2.3	1.7	1.7	3.6	3.3	2.7
Kidney & renal pelvis	4.6	3.9	2.4	2.5	1.1	3.5	3.7	4.6	6.7
Brain & CNS	5.0	2.9	1.6	1.4	1.3	1.6	4.5	2.0	2.2
Hodgkin's disease	1.1	0.9	0.5	0.1	0.3	0.5	1.3	0.1	N/A
Non-Hodgkin's lymphoma	6.3	4.3	3.2	4.2	3.8	2.4	3.5	7.1	4.4
Multiple Myeloma	3.0	6.3	1.8	1.7	1.9	2.1	2.5	3.9	3.9
Leukemia	8.9	7.4	5.3	4.9	5.1	3.7	5.4	8.1	4.4

NOTE: " " figures indicate the highest mortality rate for any racial group

DATA SOURCE: Blacks, Whites, Chinese, Japanese, Filipinos, American Indians - United States (NCHS mortality data)  
Native Hawaiian - Hawaii  
Hispanic - New Mexico, 1977-82  
Alaska Native - Alaska, 1977-83

APPENDIX D. TABLE D.1 FIVE-YEAR RELATIVE SURVIVAL PERCENTAGE BY RACE AND CANCER SITE

Five-Year Cancer Relative Survival Percentage by Race and Cancer Site, Both Sexes, 1975-84									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Natives
All sites	50.3	38.6	46.5	51.8	45.6	35.2	46.6	43.2	N/A
Oral cavity & pharynx	49.7	33.5	55.9	46.7	48.8	33.7	62.6	42.6	N/A
Esophagus	6.7	4.2	10.8	6.8	3.5	•	0.0	0.0	N/A
Stomach	16.5	17.7	20.8	28.3	18.9	7.9	17.5	13.0	N/A
Colon & rectum	53.1	45.4	53.0	60.1	45.4	38.0	44.1	58.2	N/A
Liver	4.2	3.7	2.5	1.7	6.2	0.0	0.0	5.1	N/A
Gallbladder	9.4	8.7	•	17.1	•	5.6	8.8	•	N/A
Pancreas	2.9	4.0	3.0	2.5	5.3	0.0	1.9	0.0	N/A
Lung & bronchus	13.8	11.4	15.3	14.7	13.3	8.9	10.0	13.2	N/A
Melanoma (skin)	81.9	63.5	•	81.6	•	•	79.8	•	N/A
Breast*	75.7	62.8	81.0	85.4	73.5	48.8	70.3	69.4	N/A
Cervix uteri*	67.2	61.3	75.7	71.1	73.7	65.1	71.0	67.3	N/A
Corpus & Uterus NOS*	84.6	56.3	84.7	84.9	80.5	82.6	75.3	76.3	N/A
Ovary*	38.2	40.1	46.4	44.0	44.9	47.2	38.3	50.6	N/A
Prostate gland#	69.8	62.0	72.4	79.8	68.4	51.4	71.4	73.5	N/A
Urinary bladder	76.4	53.8	78.2	81.6	59.7	•	66.6	51.5	N/A
Kidney & renal pelvis	51.9	51.9	54.0	58.8	47.5	38.1	49.2	51.6	N/A
Brain & CNS	22.4	29.1	32.3	37.9	31.1	39.5	33.9	40.6	N/A
Hodgkin's disease	74.1	71.0	•	•	45.6	•	66.8	•	N/A
Non-Hodgkin's lymphoma	50.5	48.2	50.0	42.6	35.6	33.5	41.2	42.5	N/A
Multiple Myeloma	25.9	29.4	26.5	31.8	20.8	33.7	28.3	31.2	N/A
Leukemia	35.4	30.9	21.0	25.0	21.6	21.4	26.6	23.8	N/A

DATA SOURCE: Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut NOTE: " " figures represent lowest survival percentage of any racial group  
Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii  
American Indian - New Mexico, Arizona  
Hispanic - New Mexico  
Native Hawaiian - Hawaii  
"•" indicates less than 25 first year cases  
"••" indicates female data only  
"•#" indicates male data only



Five-Year Cancer Relative Survival Percentage by Race and Cancer Site, Females Only, 1975-84									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	56.2	45.2	55.5	60.5	56.3	40.6	49.3	52.2	N/A
Oral cavity & pharynx	54.6	45.8	59.5	54.2	58.4	•	64.8	36.4	N/A
Esophagus	8.4	7.2	•	•	•	•	•	•	N/A
Stomach	18.7	18.6	25.8	29.5	8.4	12.0	15.8	14.2	N/A
Colon & rectum	53.6	47.6	58.1	61.0	50.4	42.3	46.4	59.7	N/A
Liver	6.5	6.7	4.5	3.7	•	•	•	•	N/A
Gallbladder	9.4	8.6	•	16.6	•	6.4	10.3	•	N/A
Pancreas	2.7	4.8	5.7	4.7	7.2	0.0	2.2	•	N/A
Lung & bronchus	17.1	15.0	16.7	9.2	11.4	14.1	12.3	17.0	N/A
Melanoma (skin)	87.1	69.9	•	•	•	•	74.4	•	N/A
Breast	75.7	62.8	81.0	85.4	73.5	49.7	70.3	69.4	N/A
Cervix uteri	67.2	61.3	75.7	71.1	73.7	65.1	71.0	67.3	N/A
Corpus & Uterus NOS	84.6	56.3	84.7	84.9	80.5	82.6	75.3	76.3	N/A
Ovary	38.2	40.1	46.4	44.0	44.9	47.2	38.3	50.6	N/A
Urinary bladder	73.5	43.2	67.6	70.1	•	•	47.0	•	N/A
Kidney & renal pelvis	51.8	55.6	•	62.7	•	36.2	38.2	•	N/A
Brain & CNS	23.6	31.6	•	48.4	•	•	40.5	49.0	N/A
Hodgkin's disease	76.4	72.5	•	•	•	•	76.7	•	N/A
Non-Hodgkin's lymphoma	51.1	53.6	49.7	43.6	36.6	•	39.5	47.0	N/A
Multiple Myeloma	26.3	30.1	•	•	•	•	31.0	•	N/A
Leukemia	35.6	31.9	15.9	29.8	23.1	31.8	27.6	24.8	N/A
DATA SOURCE: Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut NOTE: "•" figures represent lowest survival percentage of any racial group Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii American Indian - New Mexico, Arizona Hispanic - New Mexico Native Hawaiian - Hawaii "•" indicates less than 25 first year cases									

Five-Year Relative Survival Percentage by Race and Cancer Site, Males Only, 1975-84									
Cancer Site	White	Black	Chinese	Japanese	Filipino	American Indian	Hispanic	Native Hawaiian	Alaska Native
All sites	43.5	32.7	37.7	43.2	38.3	28.0	43.7	32.8	N/A
Oral cavity & pharynx	47.2	28.0	54.1	43.7	43.9	28.0	61.8	46.8	N/A
Esophagus	5.9	3.2	6.6	6.1	4.2	•	0.0	0.0	N/A
Stomach	15.1	17.2	17.2	27.6	22.7	4.7	18.6	12.1	N/A
Colon & rectum	52.8	42.8	49.2	59.5	43.4	33.0	41.8	57.7	N/A
Liver	2.8	2.1	2.2	1.2	4.2	•	0.0	0.0	N/A
Gallbladder	9.4	8.9	•	•	•	3.0	•	•	N/A
Pancreas	3.0	3.2	0.0	0.8	4.4	0.0	1.5	0.0	N/A
Lung & bronchus	12.1	10.1	14.6	13.1	13.9	5.8	8.6	11.4	N/A
Melanoma (skin)	76.8	51.6	•	•	•	•	88.7	•	N/A
Breast	79.2	80.8	•	•	•	•	•	•	N/A
Prostate gland	69.8	62.0	72.4	79.8	68.4	51.4	71.4	73.5	N/A
Urinary bladder	77.4	59.7	80.9	86.5	66.4	•	73.4	61.2	N/A
Kidney & renal pelvis	51.9	49.4	54.3	56.3	44.0	39.2	55.6	39.3	N/A
Brain & CNS	21.4	27.2	25.1	29.0	29.2	43.8	30.8	•	N/A
Hodgkin's disease	72.2	70.2	•	•	•	•	62.1	•	N/A
Non-Hodgkin's lymphoma	49.8	43.5	50.2	40.9	35.1	•	42.7	39.1	N/A
Multiple Myeloma	25.6	28.8	•	•	9.5	•	24.8	•	N/A
Leukemia	35.2	29.9	24.6	21.4	20.5	12.6	25.7	23.1	N/A
<b>DATA SOURCE:</b> Blacks, Whites - San Francisco-Oakland, Atlanta, Detroit, Connecticut Chinese, Japanese, Filipino - San Francisco-Oakland, Hawaii American Indian - New Mexico, Arizona Hispanic - New Mexico Native Hawaiian - Hawaii									
<b>NOTE:</b> "•" figures represent lowest survival percentage of any racial group "•" indicates less than 25 first year cases									

## **APPENDIX E. EXCERPT FROM THE IHS STUDY, "CANCER INCIDENCE IN AMERICAN INDIANS AND ALASKA NATIVES"**

This appendix includes an excerpt of a paper which has been accepted for publication by the *American Journal of Public Health* (AJPH). At the time of submitting this monograph for publication, the AJPH issue with the description of the IHS study had not been released. For a complete description of the study, see the appropriate AJPH issue.

A brief overview, description of methodology, uses of study results, and limitations of findings is provided below. The tables on the following pages include the eight cancer sites which were described in Chapter 4 and are excerpts from the IHS AJPH paper.

### **Overview**

The Indian Health Service conducted a research study (1993) on cancer incidence among American Indians and Alaska Natives. This study utilized hospital discharge data for 1980-87 to identify cases of cancer for 21 sites in females and 18 sites in males. Cancer sites were selected for inclusion in the analysis if their rate in either sex (directly age-adjusted to the 1970 U.S. population) was greater than 10 per 100,000 person-years, or if published studies suggested a rate which was significantly different than in the non-Indian population. The IHS Inpatient Data System includes a standard data set for each patient discharged from an IHS or contract facility.

### **Methodology**

An incident case during the study time frame was identified as an individual with a site-specific cancer diagnosis during 1982-87, with no cancer diagnosis at the same site in 1980-81. In computing tribal specific rates, incident cases were attributed to a tribal group based on both tribal affiliation code and the community of residence at the time of initial cancer diagnosis. Ninety-five percent confidence intervals were computed for each rate. The principal analysis compared rates computed for nine IHS Areas and nine major tribal groups with rates reported for U.S. whites from the SEER Program for 1982-87.

### **Uses of Study Results**

Regional incidence data are available on Native American cancer incidence. However, this is the first study to examine incidence cancer rates across a broad cross-section of the American Indian and Alaska Native population of the U.S., using methods that compare Indigenous Peoples rates with those in the general population as well as comparing rates among Native American groups.

Knowledge of data variation is useful to support rational planning, development of clinical policies, and resource allocation across the diverse communities served by the IHS and independent Indigenous communities. The magnitude of variation is often extreme, e.g., lung cancer rates are 13-14 fold higher among females of Alaska and Bemidji than among Navajo. The study demonstrates the variation in cancer burden within the IHS service population and underscores the danger inherent in generalizing health issues across the many distinct American Indian and Alaska Native communities and tribal groups. The study also illustrated

the variation that exists within an IHS Area that is only apparent on tribal-specific analysis. For example, within the Phoenix Area, cancer of the uterus is elevated among Tohono O'odham and Pima women, but decreased among Apache women.

### **Limitations of the Findings**

Discharge data probably under-estimate some cancers that do not require hospitalization, and under-utilization of the IHS health care system may further undercount cancer that is cared for in the community. The degree of underestimation may vary by IHS Area and by tribal group. Selected groups were excluded from both numerator counts and from the estimation of the population at risk for IHS hospitals which do not report inpatient discharge data and for areas which IHS staff believes use non-IHS facilities. Many of the incidence rates reported are based on relatively small numbers when disaggregated to the IHS Area or tribal level. Nonetheless, the findings are useful in generating hypothesis for more detailed study.

Table E.1. Female Age-adjusted Cancer Incidence rates per 100,000 population (1970 U.S. population) and 95% confidence intervals for 9 IHS Areas.

CANCER SITES (ICD-9 CODE)	ABERDEEN n = 43,574	ALASKA n = 30,189	ALBUQUERQUE n = 29,894	BEMIDJI n = 7,685	BILLINGS n = 25,489	NAVAJO n = 101,678	OKLAHOMA n = 110,343	PORTLAND n = 27,782	PHOENIX n = 61,881	SEER WHITES
STOMACH (151.0-150.9)	9.0 (3.1-14.9)	8.9 (1.8-16.0)	18.6 (8.0-29.2)	6.8 (0.0-20.1)	5.0 (0.0-10.0)	9.5 (5.8-13.4)	3.9 (2.1-5.8)	1.5 (0.0-4.4)	5.8 (1.8-9.4)	4.7
COLORECTAL (163.0, 164.1, 169.0)	16.4 (8.5-24.3)	90.2 (66.8-113.6)	22.0 (10.4-33.7)	57.7 (22.5-92.8)	19.2 (7.6-30.8)	9.5 (5.7-13.3)	18.5 (14.5-22.6)	19.7 (9.1-30.4)	13.1 (7.2-19.1)	43.5
GALLBLADDER (158.0)	4.6 (0.6-8.6)	14.4 (4.9-23.9)	6.7 (0.1-13.3)	5.3 (0.0-15.8)	2.8 (0.0-7.0)	9.8 (5.8-13.6)	3.0 (1.4-4.6)	5.8 (0.0-11.2)	18.1 (9.7-22.5)	1.4
PANCREAS (157.0-157.9)	10.5 (4.4-18.7)	11.0 (3.1-18.9)	5.8 (0.1-11.6)	9.8 (0.0-23.4)	4.0 (0.0-9.5)	6.5 (3.2-9.8)	2.1 (0.7-3.5)	4.8 (0.0-10.5)	3.9 (0.7-7.2)	8.0
LUNG (192.2-192.9)	32.1 (21.3-43.0)	58.4 (40.8-76.1)	12.1 (3.5-20.6)	52.3 (18.0-86.5)	37.8 (22.0-53.5)	4.1 (1.4-8.8)	12.1 (8.8-15.4)	10.3 (2.8-18.0)	10.9 (5.6-16.1)	36.3
BREAST (174.0-174.9)	46.7 (34.2-59.3)	51.5 (36.9-67.0)	19.5 (8.6-29.4)	20.4 (0.6-40.2)	42.2 (26.6-58.0)	28.0 (19.8-32.2)	30.9 (25.6-36.1)	20.1 (9.2-31.0)	18.8 (12.8-25.0)	105.0
CERVIX (180.0-180.9)	23.5 (15.3-31.6)	29.5 (18.3-40.7)	31.3 (18.7-43.8)	10.8 (0.0-26.2)	32.3 (18.6-45.8)	24.4 (18.5-30.4)	11.4 (8.3-14.5)	8.8 (2.7-14.8)	20.5 (13.7-27.2)	7.8

Table E.2. Male Age-adjusted Cancer Incidence rates per 100,000 population (1970 U.S. population) and 95% confidence intervals for 9 IHS Areas.

CANCER SITES (ICD-9 CODE)	ABERDEEN n = 41,977	ALASKA n = 31,130	ALBUQUERQUE n = 28,219	BEMIDJI n = 7,498	BILLINGS n = 25,055	NAVAJO n = 95,660	OKLAHOMA n = 107,893	PORTLAND n = 27,409	PHOENIX n = 59,503	SEER WHITES
STOMACH (151.0-150.9)	10.7 (4.7-16.8)	24.4 (14.2-34.7)	20.1 (9.6-30.6)	5.9 (0.0-17.4)	7.2 (0.8-13.7)	10.3 (6.4-14.2)	4.0 (2.1-6.0)	9.4 (2.7-16.1)	8.6 (4.1-13.0)	10.7
COLORECTAL (163.0, 164.1, 169.0)	20.2 (11.6-28.8)	50.6 (35.2-66.0)	6.9 (1.4-12.3)	58.0 (23.7-92.3)	17.1 (7.1-27.1)	8.2 (4.7-11.7)	11.8 (8.4-15.1)	14.2 (5.8-22.8)	8.9 (4.3-13.5)	61.7
GALLBLADDER (158.0)	2.9 (0.0-6.3)	3.5 (0.0-7.8)	6.1 (0.1-12.1)	5.2 (0.0-16.5)	1.6 (0.0-4.7)	3.8 (1.4-6.2)	0.5 (0.0-1.2)	1.5 (0.0-4.5)	3.8 (0.8-6.9)	0.8
PANCREAS (157.0-157.9)	5.8 (1.2-10.4)	14.1 (6.3-21.9)	5.8 (0.1-11.1)	16.6 (0.0-36.4)	5.3 (0.0-10.8)	6.9 (3.7-10.2)	3.8 (1.9-5.7)	3.2 (0.0-7.8)	3.8 (0.8-6.9)	10.8
LUNG (192.2-192.9)	46.2 (33.1-59.2)	86.2 (66.6-104.7)	14.4 (6.4-23.4)	42.3 (12.9-71.7)	56.4 (38.0-74.8)	12.3 (8.0-16.5)	28.4 (23.2-33.6)	12.8 (6.0-20.0)	6.3 (2.4-10.3)	82.5
PROSTATE (174.0-174.9)	30.8 (20.2-41.6)	33.2 (20.6-45.7)	34.3 (20.8-48.1)	33.1 (18.6-59.8)	43.0 (26.7-59.4)	25.6 (19.8-31.7)	20.5 (16.1-25.0)	27.0 (14.5-39.5)	14.4 (8.4-20.5)	88.0

Table E.3. Female Age-adjusted Cancer Incidence rates per 100,000 population (1970 U.S. pop.) and 95% C.I. for each of the nine major tribal groups.

CANCER SITES (ICD-9 CODE)	ALEUT n = 3,834	APACHE n = 12,781	ATHAPASKAN n = 4,474	EASTERN CHEROKEE n = 3,673	ESKIMO n = 17,252	NAVAJO n = 89,815	OKLAHOMA CHEROKEE n = 40,795	SIoux n = 27,348	TOHONO O'ODHAM/PIMA n = 14,360	SEER WHITES
STOMACH (151.0-160.8)	6.9 (0.0-20.5)	7.9 (0.0-17.0)	7.3 (0.0-21.5)	7.4 (0.0-21.8)	12.2 (0.7-23.7)	10.9 (8.5-15.4)	2.5 (0.1-5.0)	11.3 (2.8-19.7)	10.9 (0.0-22.1)	4.7
COLORECTAL (153.0, 164.1, 169.0)	88.8 (28.9-162.9)	13.0 (0.1-25.8)	98.2 (31.9-160.5)	26.7 (0.0-53.7)	116.1 (80.9-161.3)	10.7 (8.4-15.0)	26.1 (18.0-34.2)	19.4 (8.7-30.2)	9.4 (0.0-20.0)	43.5
GALLBLADDER (158.0)	0	20.5 (5.0-35.9)	0	10.7 (0.0-31.8)	27.6 (10.2-44.9)	10.8 (8.3-15.4)	2.8 (0.1-5.1)	5.9 (0.1-11.7)	33.4 (13.5-63.4)	1.4
PANCREAS (157.0-167.8)	36.4 (0.3-72.5)	3.9 (0.0-11.4)	34.0 (0.0-73.6)	7.4 (0.0-21.8)	2.4 (0.0-7.0)	7.4 (3.8-11.2)	2.6 (0.1-5.2)	13.4 (4.5-22.3)	3.4 (0.0-10.1)	8.0
LUNG (162.2-162.9)	101.7 (37.2-166.3)	8.3 (0.0-17.7)	111.3 (50.1-172.4)	35.2 (0.4-69.8)	53.2 (30.5-75.8)	4.6 (1.6-7.6)	18.4 (10.0-22.9)	34.1 (20.0-48.1)	17.9 (3.5-32.3)	38.3
BREAST (174.0-174.9)	40.1 (0.0-81.4)	26.2 (8.7-42.8)	108.1 (48.3-163.9)	43.8 (8.3-78.8)	50.7 (30.4-70.8)	28.7 (21.8-35.8)	37.7 (28.0-47.4)	57.9 (40.0-76.7)	18.5 (5.7-31.3)	105.0
CERVIX (180.0-180.8)	29.7 (0.0-51.9)	31.8 (14.1-49.5)	39.4 (4.1-74.8)	24.4 (0.0-52.0)	33.1 (17.9-48.3)	26.3 (18.7-32.8)	10.7 (6.7-16.7)	29.2 (17.7-40.8)	41.7 (21.5-62.0)	7.8

Table E.4. Male Age-adjusted Cancer Incidence rates per 100,000 population (1970 U.S. pop.) and 95% C.I. for each of the nine major tribal groups.

CANCER SITES (ICD-9 CODE)	ALEUT n = 3,953	APACHE n = 12,134	ATHAPASKAN n = 4,612	EASTERN CHEROKEE n = 3,611	ESKIMO n = 17,789	NAVAJO n = 84,502	OKLAHOMA CHEROKEE n = 37,130	SIoux n = 26,144	TOHONO O'ODHAM/PIMA n = 13,632	SEER WHITES
STOMACH (151.0-160.8)	37.4 (4.1-70.7)	13.4 (1.3-25.5)	15.3 (0.0-37.0)	9.7 (0.0-26.6)	28.9 (13.9-43.9)	10.8 (8.5-15.1)	5.6 (1.7-9.5)	11.3 (3.3-19.2)	12.2 (1.1-23.3)	10.7
COLORECTAL (153.0, 164.1, 169.0)	114.8 (47.3-182.3)	9.3 (0.0-19.9)	40.4 (4.8-75.8)	33.5 (0.6-66.5)	53.2 (32.7-73.7)	9.3 (5.3-13.3)	12.2 (6.4-18.0)	24.7 (12.6-36.8)	1.3 (0.0-3.8)	61.7
GALLBLADDER (158.0)	0	0	9.2 (0.0-27.2)	0	3.8 (0.0-9.1)	3.9 (1.3-6.4)	0	4.7 (0.0-10.0)	5.3 (0.0-12.8)	0.8
PANCREAS (157.0-167.8)	16.4 (0.0-39.2)	3.3 (0.0-9.7)	20.7 (0.0-44.1)	9.7 (0.0-25.8)	16.7 (4.6-26.7)	7.8 (4.2-11.5)	5.0 (1.3-8.7)	6.2 (0.1-12.3)	0	10.8
LUNG (162.2-162.9)	92.3 (34.7-149.8)	6.1 (0.0-14.6)	88.4 (36.3-140.5)	26.8 (0.0-57.2)	106.1 (77.3-134.8)	13.1 (8.4-17.9)	35.0 (25.4-44.8)	46.2 (28.7-62.7)	10.5 (0.2-20.9)	82.5
PROSTATE (174.0-174.9)	47.3 (5.7-88.0)	3.3 (0.0-9.7)	91.8 (37.6-146.0)	74.8 (23.1-126.4)	19.4 (6.7-32.1)	26.5 (18.9-33.1)	26.5 (18.1-35.0)	32.5 (18.9-46.8)	29.7 (12.1-47.4)	88.0

## APPENDIX F. THE TRADITIONAL AND CONTEMPORARY FOOD CONSUMPTION PRACTICES OF NATIVE AMERICANS

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### APPENDIX OBJECTIVES:

- PROVIDE REFERENCES THAT ADDRESS THE TRADITIONAL FOOD CONSUMPTION PRACTICES OF NATIVE AMERICANS AND THEIR USE OF WILD EDIBLE PLANTS.
  - PROVIDE REFERENCES THAT ADDRESS THE CONTEMPORARY HEALTH CONCERNS, FOOD CONSUMPTION PRACTICES, AND NUTRIENT INTAKES OF AMERICAN INDIANS AND ALASKA NATIVES.
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### INTRODUCTION

Appendix F includes two sections. The first includes information on what is known about the traditional food customs and practices of American Indians and Alaska Natives, and their use of wild edible plants. The second section provides references that address contemporary health concerns, what is known about their alcohol and nutrient intakes, and the nutrient composition of foods consumed between 1931 and 1992. These references can be used to:

- . *identify* the existing gaps in baseline information about the traditional and contemporary food consumption of different tribes.
- . *compare* the traditional and contemporary consumption practices of tribes where there is ample information, and compared the profile with incidence rates of various diseases.
- . *document* dietary problems and nutrient deficiencies.
- . *profile* tribal similarities or differences in alcohol and food consumption patterns or nutrient intakes, methods of food preparation, and incidence rates of diseases.

With few exceptions, book, pamphlet and proceeding titles are listed as author, title, publisher and location, date of publication and page numbers when available. Journal articles are listed by the last name and initials of the author(s), title, publication, year published, volume, and page numbers.

## SECTION I. TRADITIONAL CONSUMPTION PRACTICES OF NATIVE AMERICANS

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## SECTION II. CONTEMPORARY HEALTH CONCERNS AND FOOD CONSUMPTION PRACTICES OF NATIVE AMERICANS

### A. CONTEMPORARY HEALTH CONCERNS OF NATIVE AMERICANS

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